REPORT

OF THE CALIFORNIA CONFERENCE ON REHABILITATION

October 1974

Sacramento

sensory disabilities

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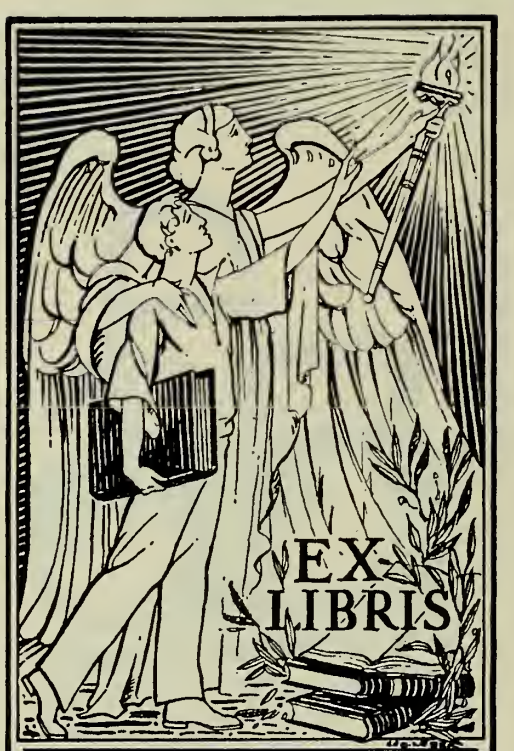

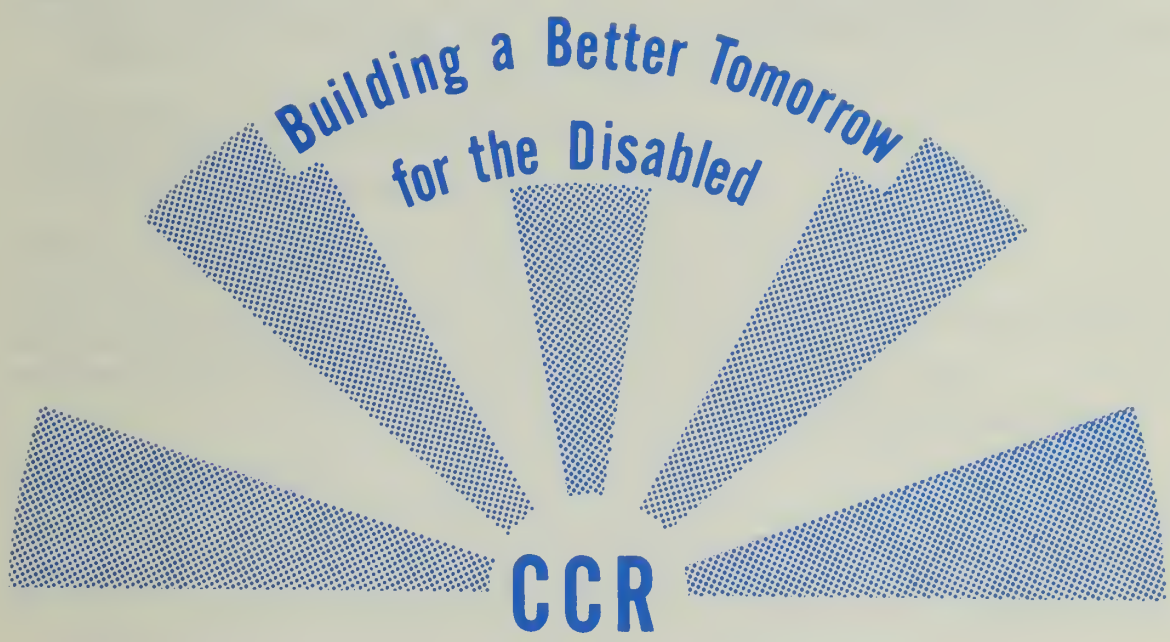

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May 1, 1975

Conference Participants:

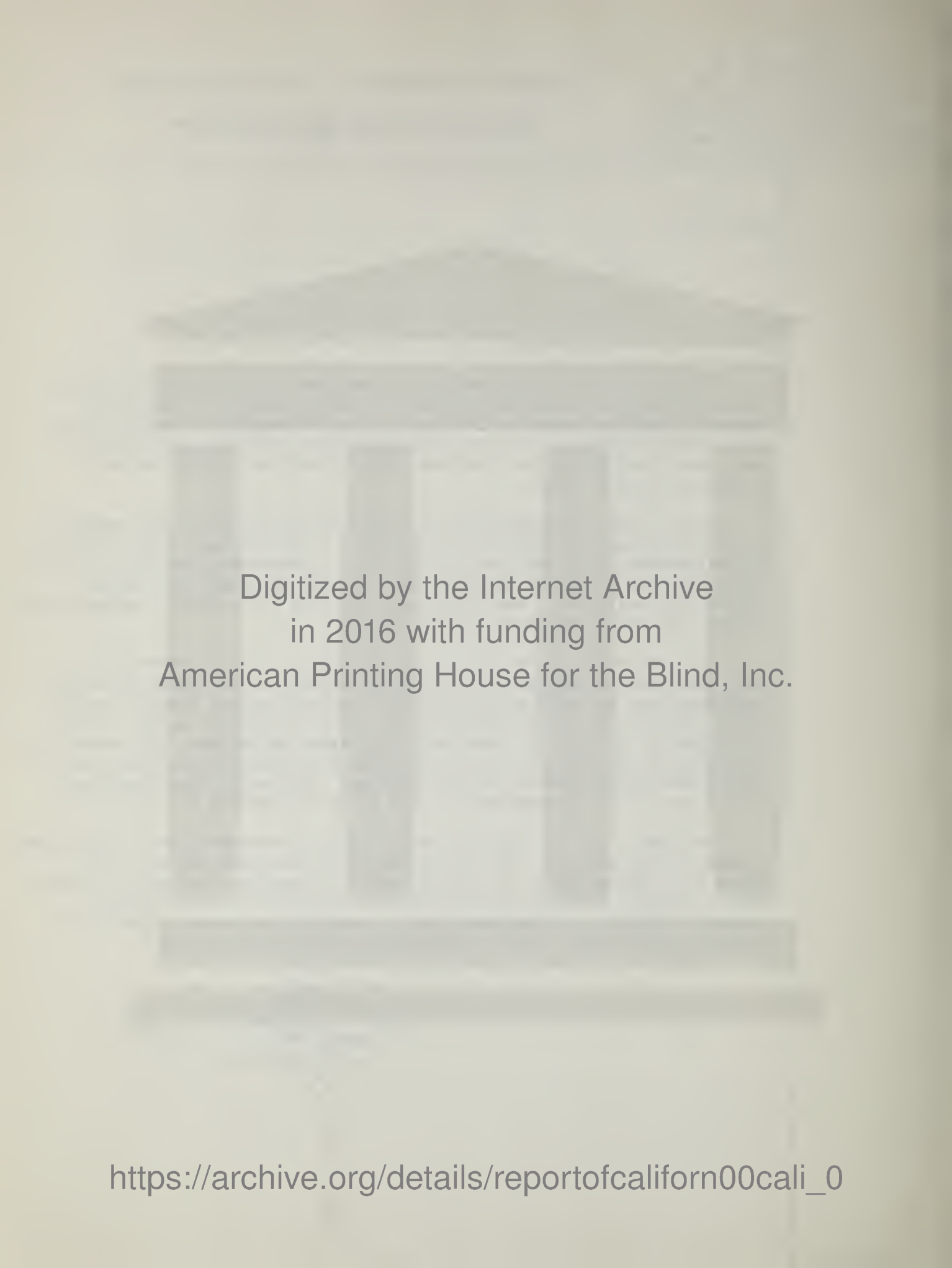
This report on the proceedings and recommendations of the California Conference on Rehabilitation clearly identifies many of the needs of severely disabled people in California. The Department of Rehabilitation will study carefully all of the recommendations and will report back to Conference participants on the Department's position on each and any actions we plan to take.

Many of the recommendations go beyond the authority or the resources of the Department of Rehabilitation alone. If the recommendations are to be implemented, each Conference participant - consumers, providers of services and rehabilitation professionals, as well as others who did not attend the Conference - must take responsibility for actively seeking ways to meet the needs expressed in this report.

The Conference proved that a partnership in rehabilitation is not only feasible but necessary. In order to encourage this partnership, the Department has recently adopted a policy to initiate and foster biennial state conferences on rehabilitation and local conferences during the interim years. In order to carry out this policy and enhance the partnership we will need the help of all organizations and individuals who are concerned with rehabilitation of the disabled. This policy has been adopted in response to the recommendation made at the Conference in October 1974.

Because of the far reaching nature of the recommendations, I am sending copies of this report to Governor Brown, the Health and Welfare Agency, other State Departments, the Legislature, the Congress and the U.S. Department of Health, Education and Welfare. I am confident that through a concerted effort of all of these public agencies and those of you in the private sector, many of the recommendations will be implemented.

HARRY TOWNE
Acting Director



HIGHLIGHT ON THE 1974 CALIFORNIA CONFERENCE ON REHABILITATION

In conception, the California Conference on Rehabilitation was intended to provide an opportunity for consumers, consumer advocates, providers and purchasers of rehabilitation services to study the needs for comprehensive services for the severely disabled. The Conference was entitled "Building a Better Tomorrow for the Disabled". This involvement of the consumer - and thus the utilization of all human resources - was the heart and promise of the Conference.

The Conference helped to facilitate some organization, some strength, some identity, some pride and some power in the disabled themselves. The disabled saw in themselves the inherent responsibility to be involved and to participate.

The Conference had a goal of developing a coordinated and integrated plan of action to assure the availability of needed services. The following recommendations were made:

1. THAT A TEST IN THE COURTS IN THE STATE BE UNDERTAKEN TO ESTABLISH THE INHERENT RIGHT OF A DISABLED PERSON TO OBTAIN NECESSARY ADAPTIVE AIDS TO FUNCTION INDEPENDENTLY IN THE COMMUNITY.

2. THAT THE STATE LEGISLATURE AND CONGRESS PROVIDE THE AUTHORITY AND FUNDS FOR A PROGRAM OF SERVICES TO DEVELOP AND MAINTAIN INDEPENDENT LIVING SKILLS IN SEVERELY DISABLED PEOPLE WHO MAY NOT HAVE VOCATIONAL POTENTIAL.

3. THAT LEGISLATION BE INTRODUCED TO PROVIDE FOR A REALISTIC SLIDING SCALE FOR DEDUCTING EARNED INCOME FROM SSI. SUCH LEGISLATION SHOULD BE PROMOTED BY CONSUMER GROUPS AND THE HEALTH AND WELFARE AGENCY.

4. THAT THE DEPARTMENT OF REHABILITATION CHANGE ITS ACCOUNTABILITY SYSTEM IN ORDER TO ENCOURAGE COUNSELORS TO WORK WITH SEVERELY DISABLED PEOPLE. GAINFUL EMPLOYMENT SHOULD NOT BE THE ONLY CRITERIA FOR SUCCESSFUL REHABILITATION.

5. THAT THE DEPARTMENT OF REHABILITATION AND OTHER GOVERNMENTAL AGENCIES SERVING THE DISABLED SHOULD DEVELOP A CLEAR STATEMENT OF THE RIGHTS HANDICAPPED PEOPLE HAVE TO SERVICES PROVIDED BY THESE AGENCIES. AGENCY PUBLIC INFORMATION PROGRAMS SHOULD BE INSTITUTED TO INFORM HANDICAPPED PEOPLE OF THESE RIGHTS.

6. THAT THE DISABLED THEMSELVES BEGIN TO ORGANIZE AND EXTEND THEIR EFFORTS TO ALLEVIATE THE PROBLEMS OF ALL HANDICAPPED PEOPLE. THE VALUE OF SELF-HELP ORGANIZATIONS WAS REPEATEDLY ENDORSED.

7. THAT THE DEPARTMENT OF REHABILITATION ACTIVELY PURSUE ARCHITECTURAL BARRIER LAW ENFORCEMENT. FEPC LEGISLATION MUST BE PUSHED BY THE DEPARTMENT OF REHABILITATION TO INCLUDE THE MENTALLY DISABLED. ATTITUDINAL BARRIERS WITHIN THE DEPARTMENT MUST BE ATTACKED. BARRIERS, ARCHITECTURAL AND ATTITUDINAL, LIMIT DISABLED PEOPLE TO DEPENDENT STATUS.

In summary, the Department of Rehabilitation was repeatedly cast in a strong advocacy role: an advocate for the disabled in purusing needed legislation; an advocate for the disabled in approaching local government; an advocate for the disabled in approaching other governmental agencies; and, an advocate for the disabled in assisting them to organize themselves.

The California Conference on Rehabilitation resulted in over 100 specific recommendations for action. Only a few of these recommendations have been mentioned here. Although the Department of Rehabilitation was seen as the focal point for initiating and encouraging action by all levels of government, the Conference identified the Department of Rehabilitation, the disabled and providers of service as working partners in the task that needs to be accomplished.

This report represents the views of those disabled and non-disabled people who attended the California Conference on Rehabilitation or participated in the pre-Conference inquiries or study groups. There are many disabled people who were not able to participate or articulate their views due to the nature of their disability or other special circumstances.

OVERVIEW OF THE CALIFORNIA CONFERENCE ON REHABILITATION, OCTOBER 1974

PLANNING FOR THE CONFERENCE

It all started when the Executive Staff of the Department of Rehabilitation agreed that Norman Evans, Regional Administrator for the Bay Area Region of the Department of Rehabilitation, should explore with representatives of organizations of the disabled and providers of services their interest in having a state conference on rehabilitation. No such statewide conference had been held in California since 1957.

In February 1974 a meeting was held of people representing the Department and outside organizations to explore interest in such a conference. The initial reaction at this meeting was that we should not have a conference just to have a conference. The group felt strongly that any such conference should have a purpose which went beyond the conference itself. It was agreed that the Conference should attempt to identify the unmet needs of all disabled people, and begin to develop cooperative efforts of public and private organizations in meeting these needs.

PURPOSE OF THE CONFERENCE

Following this meeting the Department of Rehabilitation agreed to sponsor a California Conference on Rehabilitation in October 1974. The purpose of the Conference was to provide an opportunity for consumers, consumer advocates, providers and purchasers of rehabilitation services to study the needs for comprehensive services for the severely disabled as provided for in the Rehabilitation Act of 1973. It was further specified that the Conference would make a report of the needs and recommendations for meeting those needs to the Department of Rehabilitation, the Governor, the legislature, the Department of Health, Education and Welfare and to other interested parties. The goal of the Conference was to develop a coordinated and integrated plan of action to assure the availability of the needed services. The Conference would be directed to identifying the needs, gaps in service and methods of meeting the needs of severely disabled people in the areas ranging from life preservation to physical, personal, social, vocational and economic independence. In order to assure that consideration be given to all disability groups, major disability target groups were identified as physical disabilities, mental disabilities, developmental disabilities, sensory disabilities and internal disabilities. This latter group was further broken down into cardiac, respiratory and renal disabilities.

PRECONFERENCE STUDY GROUPS

In April 1974, the momentum began to pick up when a steering committee was established consisting of representatives of the Department of Rehabilitation and organizations concerned with each of the major disability target groups. The steering committee set up study groups for each of the disability categories. The purpose of the study groups was to obtain as much input as possible from consumers, consumer advocates, providers and purchasers of rehabilitation services

prior to the Conference in order to be able to present the issues and unmet needs at the Conference.

The study groups met from June through September 1974. The developmental disabilities and neuro-musculo-skeletal disabilities study groups held public inquiries throughout the state. The other study groups drew upon the expertise of a wide variety of individuals including consumers and conducted special studies and surveys to obtain input. By the time the Conference started, hundreds of people throughout the state had been involved in the planning or had provided input to the study groups. As the result of this involvement over 1,100 people registered to attend the Conference and many more attended special sessions. It is recognized that many severely disabled people were not able to attend the pre-Conference meetings or the conference and could not make their views known because of the nature of their disabilities.

THE CONFERENCE

It is not possible to adequately describe the spirit and the tone that pervaded the California Conference on Rehabilitation. Something happened at the Conference which had to be experienced to be understood. There was a sense of working together, a spirit of understanding and of learning from one another. Some of the traditional hostilities, frustrations and antagonisms were expressed but seemingly with the desire to do something together to resolve them.

The major work of the Conference took place in the section meetings devoted to reports and discussions by the study groups focused on the needs of particular disability groups. The issues and recommendations developed in these section meetings are described later in this report.

The general sessions of the Conference provided an opportunity to stimulate the Conference participants for the work of the various sections. The closing session was devoted to summarizing the work of each section and indicating directions for the future.

THE OPENING SESSION

In the opening general session the keynote speaker, E.B. Whitten, Executive Director of the National Rehabilitation Association, highlighted the provisions of the Rehabilitation Act of 1973. Mr. Whitten emphasized that the major sections of this Act were focused on provision of rehabilitation services in order to accomplish a vocational objective. He emphasized the priority which must be given to serving the severely disabled who have potential for achieving a vocational objective. Mr. Whitten stressed that the Act did not provide for rehabilitation services for disabled individuals who do not have potential for achieving a vocational objective, but who could become more independent if rehabilitation services were provided. He discussed the provisions of the Act for a study of the comprehensive service needs of severely disabled people including those who may not be able to achieve a vocational objective. The Act requires that a report of this study, to be conducted by the Secretary of Health, Education and Welfare, must be made to Congress. While Mr. Whitten effectively outlined the limitations of the Rehabilitation Act of 1973, he offered hope and encouragement for a broader definition of rehabilitation services in future legislation.

THE BANQUET

At the Conference banquet on the evening of the first day, Mrs. Dorothy Atwood Debolt spoke dramatically and eloquently about the need for adoptive parents for "special kids". From her own experience in raising seven severely disabled adopted children, Mrs. DeBolt told of the many rewards and satisfactions she and her husband had experienced. She stressed the need for other parents to open their hearts and their homes to these unwanted children.

THE SECOND DAY - GENERAL SESSION

The second day opened with a general session attended by a capacity crowd in anticipation of a psycho-drama to be presented by Dr. William Rader. The psycho-drama was concerned with the consumer as a member of the team. This turned out to be one of the most talked about and stimulating sessions of the Conference. Dr. Rader effectively involved the 1,100 conference participants who attended this session even though only about a half dozen people engaged in the psycho-drama. This session dramatically demonstrated the difficulties in communications between professional people and the people they are trying to serve. Dr. Rader emphasized the need for professional people to be able to talk to their disabled clients on a human level rather than hiding behind their professional status. His presentation demonstrated that such things as posture, facial expressions, hand-shakes and other physical characteristics or actions may communicate something very different than the words being used at the time. He stressed the need for the helping person to listen to the feelings expressed by disabled people without anxiety that you must be able to solve all the problems. Disabled people on the other hand must learn to openly express their feelings, their anxieties and their frustrations and to share in a relationship with those who are trying to help. The partnership of the disabled person and the professionals in the rehabilitation process was clearly reflected through this presentation.

THE FINAL SESSION

The final afternoon of the conference was devoted to a report by representatives of each of the section meetings. These representatives presented recommendations for action which had come out of their sessions. This was followed by a panel of consumer representatives who reacted to the recommendations and the conference in general. In addition to the recommendations which are discussed in more detail in the following sections, there was an emphasis placed on the need for action following the conference and a strong recommendation that future conferences be planned on an annual or biennial basis.

Following these presentations, Dr. Andrew S. Adams, Commissioner of the Rehabilitation Services Administration, Department of Health, Education and Welfare, discussed trends in federal rehabilitation and shared with the participants experiences in his recent tour of rehabilitation facilities in Russia.

Dr. Glen Reynolds from the Santa Clara Valley Medical Center briefly summarized his impressions of what had taken place at the conference. Carolyn Vash, Chief Deputy Director of the Department of Rehabilitation, emphasized the need for all conference participants to feel responsible for taking action on the recommendations from the Conference.

CONFERENCE RECOMMENDATIONS

The following sections of this conference report present the recommendations made by each of the study groups. These recommendations are based on pre-Conference meetings and the deliberations at the conference. It is anticipated that there will be a cooperative effort from all of the individuals and organizations that participated in the conference in assuring that action is taken on the recommendations. Much work needs to be done at a local level as well as at state and federal levels. We have also tried to highlight at the beginning of this report those recommendations that were common to a number of the study groups since they affect all or many disabled people.

POSITION PAPERS

Many of the section reports that follow contain an annotated list of many of the position papers that were presented to the pre-conference study group or at the conference. Copies of these position papers may be obtained by contacting the Department of Rehabilitation, Program Planning and Development Section, 722 Capitol Mall, Sacramento, California 95814.

In order to share as much of the experience of the conference with as many people as possible, video tapes have been made of many of the conference sessions. Copies of these tapes may be borrowed by contacting the Program Planning and Development Section of the Department of Rehabilitation at the address given above. The conference recommendations are also available on tape for those who have visual problems. Tapes may be obtained by contacting the address given above.

ACKNOWLEDGEMENT

The conference planning committee wishes to acknowledge and express its thanks to the many organizations and individuals who enthusiastically and energetically participated in making this conference a success, including all of the people who attended the conference as well as those who worked on the pre-conference planning or attended study group meetings.

INTERNAL DISABILITIES
OVERVIEW

PRECONFERENCE STUDY

At the very outset it was recognized that the term "internal disabilities" is quite broad, and that it includes three of the principle diseases causing disabilities: heart disease, kidney disease and lung disease. For this reason the Internal Disabilities Study Group decided to break up into three subgroups entitled the Cardiac Study Group, the Renal Study Group and the Respiratory Study Group. Each of these three study groups attempted to broadly represent the various disciplines making up comprehensive rehabilitation teams. Each made efforts to either get consumer input or to include consumers on the study group. Each study group attempted to get representation from some of the major facilities in California that are involved in the rehabilitation of victims of heart, kidney or pulmonary disease. One of the study groups, the Cardiac Study Group, conducted a survey on the number and relative comprehensiveness of interdisciplinary cardiac rehabilitation centers.

CONFERENCE PRESENTATIONS

Since the Internal Disabilities Study Group was really three groups rather than one, each of the three meetings for section presentations during the Conference was devoted either to cardiac, renal or respiratory disease. During its section meeting the Cardiac Study Group gave a series of panel presentations from the standpoint of various disciplines or rehabilitation centers. This group also included presentations by two consumers, one of which consisted of a dialogue between Sam Ito, an ex-cardiac patient, and Len Matheson, a psychologist. This dialogue demonstrated better than any prepared text the importance of social and psychological factors in the treatment of cardiac disease; it also revealed the way in which from the standpoint of the patient treatment facilities, professional workers and government programs failed to listen and often neglected the real needs of the cardiac patient. The Renal Study Group departed from the panel presentation format in favor of free association of ideas involving both the panel members and the audience, including two chronic dialysis treatment patients who participated in impromptu dialogue with Dr. William C. Rader and other members of the panel. The Respiratory Study Group also took the formal panel presentation approach following a brief lecture and slide presentation on chronic obstructive pulmonary disease by Dr. Allen Lifshay.

Although the heart, kidneys and lungs are affected by disease processes unique in themselves, they are all vital organs crucial to life in the human being, and they are all major causes of disability. As such, each of the three study groups working separately frequently came up with common issues and common recommendations. Both the Cardiac and Respiratory Study Groups, for example, point out the need for more comprehensive rehabilitation centers which use the interdisciplinary team approach to treatment and rehabilitation. All three Study groups express concern for those policies of Medi-Cal, Medicare and private insurance carriers that fail to adequately reimburse treatment facilities for interdisciplinary rehabilitation services.

Recognizing the importance of public health care programs, the Cardiac Study Group invited a representative of the Department of Health to serve as a member of the Study Group. Both the Cardiac Study Group and the Renal Study Group saw considerable

value in self-help organizations of consumers, and recommended financial support to such consumer advocacy groups. In respect to the vocational rehabilitation of severely disabled persons, both the Cardiac and Renal Study Groups strongly recommended early involvement of the rehabilitation counselor, and, in the case of the Cardiac Study Group, early contacts by the rehabilitation counselor with the cardiac patient's current or previous employer. Workmen's Compensation Laws and practices pose serious barriers to vocational rehabilitation recognized by the cardiac and renal groups, both of which pointed out the need for changes in government codes and implementation of programs to educate employers and insurance carriers.

CARDIAC REHABILITATION CENTERS
CARDIAC DISABILITIES

ISSUE

More comprehensive cardiac rehabilitation centers should be established in California. In order to be comprehensive such centers must recognize the multiple non-medical needs of cardiac patients prior to, during and following hospitalization.

DISCUSSION

A comprehensive center would understand the value of a variety of allied health disciplines in the rehabilitation of the cardiac patient. These disciplines would include the following areas: educational, dietary, social, psychological, physical therapy, occupational therapy, exercise rehabilitation, discharge planning, financial counseling, family counseling, recreation therapy, posthospital counseling and follow up. Moreover, a center, as defined by the Cardiac Study Group, would provide cardiac rehabilitation services in addition to cardiac restoration. Restoration has the goal of returning the disabled person to the lifestyle, to the vocational, social and family roles that were interrupted by the disability. Rehabilitation, on the other hand, seeks not only to restore the patient to levels of physical and mental activity compatible with the functional capacity of the heart, but also to help the patient, with the support of his family, to achieve lasting changes in lifestyle that reduce risk factors and prevent exacerbation of the disease process. Each patient's disability would be "functionally defined" by such a center so that a variety of allied health disciplines could be coordinated to meet the individual patient's needs. A comprehensive center should provide interdisciplinary services, not just multidisciplinary services. Cohesive, well integrated and many-faceted, the interdisciplinary team would take responsibility for the holistic care of the patient. A survey conducted by the study group revealed that throughout California there are only about five comprehensive cardiac rehabilitation facilities that provide both inpatient and outpatient programs; there are a total of some ten hospitals which provide either inpatient or outpatient programs.

RECOMMENDATION

1. BOTH THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION SHOULD EXPLORE STATE AND FEDERAL SOURCES OF FUNDING FOR THE ESTABLISHMENT OF CARDIAC REHABILITATION CENTERS.

ISSUE

Since most hospitals already employ a variety of allied health professionals, there would be potential for a network of comprehensive centers throughout the state, if only the various disciplines were well coordinated and committed to a team approach to cardiac rehabilitation.

RECOMMENDATION

2. THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD, WITH THE ASSISTANCE OF DIRECTORS OF ALREADY ESTABLISHED COMPREHENSIVE CARDIAC REHABILITATION CENTERS, BEGIN MEETING WITH MEDICAL DIRECTORS, HOSPITAL ADMINISTRATORS AND REPRESENTATIVES OF OTHER MEDICAL AND PARAMEDICAL PROFESSIONS SUCH AS NURSES, PHYSICAL THERAPISTS, OCCUPATIONAL THERAPISTS, PSYCHOLOGISTS, AND MEDICAL SOCIAL WORKERS TO EXPLORE WAYS IN WHCIH IMPROVED COORDINATION OF A VARIETY OF DISCIPLINES CAN BE CARRIED OUT, WITH OR WITHOUT ADDITIONAL FUNDS.

ISSUE

The Cardiac Study Group survey learned that, where a broad spectrum of services and disciplines were present in a facility, they were not always fully utilized. This was less true when services were well coordinated, but it was somewhat true of even well coordinated programs. Services that are particularly underutilized by inpatient programs are psychological counseling, financial counseling, discharge planning and family counseling. The most underutilized outpatient program services are prehospital counseling and vocational counseling. The problem here is one of philosophy, communication and education.

RECOMMENDATION

3. THE DEPARTMENTS OF REHABILITATION, HEALTH AND EDUCATION SHOULD USE THEIR GOOD OFFICES, AGAIN WITH THE HELP OF DIRECTORS OF ESTABLISHED COMPREHENSIVE CARDIAC REHABILITATION CENTERS, AND OF PERSONS LIKE JEAN ZELLE OF UC DAVIS MEDICAL SCHOOL, TO INFLUENCE THE CURRICULA OF MEDICAL SCHOOLS, THE RESIDENTIAL TRAINING PROGRAMS OF TEACHING HOSPITALS AND THE CURRICULA OF THE VARIOUS PARAMEDICAL DISCIPLINES TO PROMOTE A COMPREHENSIVE INTERDISCIPLINARY, REHABILITATION TEAM APPROACH TO THE TREATMENT OF CARDIAC PATIENTS.

ISSUE

Early referral for vocational rehabilitation counseling of the cardiac patient is important to the patient's recovery. Early referral permits contact by a rehabilitation counselor with the patient's current or previous employer. A rehabilitation counselor reporting early and regularly to the employer on the progress of the patient can be very valuable as a means of retaining a patient's previous job or of obtaining a more appropriate job with a previous employer.

RECOMMENDATION

4. TO IMPROVE ITS PARTICIPATION IN A REHABILITATION TEAM APPROACH TO THE TREATMENT OF CARDIAC PATIENTS, THE DEPARTMENT OF REHABILITATION SHOULD PLACE CARDIAC REHABILITATION CENTERS HIGH ON ITS PRIORITY LIST AS A SOURCE FOR REFERRALS. MOREOVER, THE DEPARTMENT SHOULD ENCOURAGE AMONG REHABILITATION COUNSELORS ACTIVE CASEFINDING WITHIN MAJOR HOSPITALS WHICH WOULD RESULT IN THE EARLY REFERRAL OF THE PATIENT FOLLOWED BY VOCATIONAL COUNSELING AND PLANNING. FINALLY, THE DEPARTMENT SHOULD ENCOURAGE COUNSELORS TO BECOME MORE ACTIVE IN THE PLACEMENT OF CARDIAC PATIENTS, TO ESTABLISH EARLY RELATIONSHIPS WITH THE PATIENT'S CURRENT OR PREVIOUS EMPLOYERS AND, WHEN EMPLOYMENT THROUGH THAT SOURCE IS NOT FEASIBLE, TO EXPLORE JOB OPPORTUNITIES FOR PATIENTS WITH OTHER EMPLOYERS.

MEDI-CAL, MEDICARE AND PRIVATE INSURANCE
CARDIAC DISABILITIES

ISSUE

The costs for cardiac treatment, particularly comprehensive cardiac rehabilitation, are high. However, well coordinated comprehensive cardiac rehabilitation centers are usually able to cut short a patient's hospital stay enough to offset the additonal cost of the interdisciplinary team approach.

DISCUSSION

Most important is the fact that the sooner a patient returns home under a planned program, the more likely he is to return to work and make optimum adjustment to his disability. The patient who is rehabilitated to a productive life will no longer require so many costly services. The rehabilitated cardiac will in fact further offset the costs of his treatment by the taxes he pays out of his earnings. Nevertheless, funding available through private insurance programs, Medi-Cal or Medicare is often inadequate for comprehensive treatment of the cardiac patient. There is a conflict here between the purchaser's valid need to audit what is being purchased and the treatment facilities' need for flexibility in treating the individual cardiac disability, as functionally defined. For example, Medi-Cal apparently cannot pay for a "program", but it can pay for a well defined and well justified package of services. Cardiac rehabilitation facilities frequently have difficulty obtaining prior authorization for extensions of hospitalization, provision of rehabilitation services involving a variety of allied health service disciplines, prescription of drugs that are not on the drug formulary, the provision of home health treatment, and the provision of outpatient services. Although representatives of the Department of Health maintain that such services can be authorized under Medi-Cal if they are properly justified, rehabilitation centers suspect that Medi-Cal decisions sometimes rest upon fiscal rather than medical or rehabilitation concerns. On the other hand, Medi-Cal consultants may have legitimate suspicions of their own regarding requests for vaguely described or open-ended kinds of service.

Both sides, the rehabilitation centers on the one hand and Medi-Cal, Medicare or private insurance carriers on the other, will have to concede something to assure that the costs of more adequate treatment of cardiac patients are covered. Rehabilitation centers should recognize a legitimate need of the insurance carrier to document and justify its purchase of services to prevent abuses, keep down costs and leave a warrantable audit trail. On the other hand, health care programs and insurance carriers should put their fiscal concerns in abeyance when they are considering well justified requests for services that are above and beyond traditional acute care. In respect to public health care programs, it should be recognized that a true comprehensive team effort to rehabilitate the cardiac patient will reduce the prospect for recurrence of the disease. This means that failure to approve requests for legitimate comprehensive rehabilitation services may prove to be more expensive in the long-run, not only for society as a whole, but for the public health care program itself.

RECOMMENDATIONS

5. THE DEPARTMENT OF HEALTH SHOULD SUPPORT FUNDING FOR A THREE TO FIVE YEAR RESEARCH PROJECT COMPARING THE RELATIVE LONG-TERM COST EFFECTIVENESS OF THE CARDIOLOGIST WORKING IN A PRIVATE SETTING ON THE ONE HAND TO THE FULL SCALE TEAM EFFORT ON

6. THE OTHER, AS A BASIS FOR DEVELOPING A WORKABLE FEE SCHEDULE FOR COMPREHENSIVE, INTERDISCIPLINARY REHABILITATION SERVICES.

7. THE DEPARTMENT OF HEALTH SHOULD PROVIDE CONSULTATION TO PROVIDERS THAT WOULD ENABLE THEM TO BREAK DOWN PROGRAMS INTO PACKAGES OF SERVICES FOR WHICH THEY WOULD BE ABLE TO CHARGE A REASONABLE FEE.

ISSUE

One problem in some areas is the fact that Medi-Cal consultants may be quite distant from the providers. This problem decreases what opportunities there might be for intercommunication that might begin to resolve some of the conflicts between the public health service program and the rehabilitation center provider.

RECOMMENDATIONS

8. THE DEPARTMENT OF HEALTH SHOULD STUDY WAYS IN WHICH IT MIGHT BETTER DEPLOY MEDI-CAL CONSULTANTS TO PERMIT CLOSER COMMUNICATION WITH PROVIDERS.

9. THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD ATTEMPT TO PERSUADE PRIVATE INSURANCE CARRIERS TO BEGIN PAYING FOR COMPREHENSIVE, INTERDISCIPLINARY REHABILITATION SERVICES ON A FEE-FOR-SERVICE BASIS. IF THAT FAILS, BOTH DEPARTMENTS SHOULD USE THEIR INFLUENCE UPON THE LEGISLATURE TO CHANGE INSURANCE AND LABOR CODES IN SUCH WAYS AS TO ENCOURAGE PAYMENT FOR SUCH REHABILITATION SERVICES.

ISSUE

As pointed out above, there are not enough comprehensive cardiac rehabilitation centers. Even as more are developed, there will still be many hospitals without cardiac rehabilitation services which will be treating just a medical diagnosis, not a disability, as functionally defined. This means that many cardiac patients will continue to have needs that are not being met. Special projects have shown that special hospital and nursing services can partially fill this gap in services.

DISCUSSION

The San Francisco Heart Association has, for the past two and a half years, served cardiac patients in six major San Francisco hospitals. The project, which is scheduled to expire June, 1975 due to lack of funds, provides a nurse who begins to teach the patient in such areas as anatomy, physiology, exercise, diet, medications, sexual activity and risk factors within one week of the acute cardiac episode. At about the same time the nurse meets with the patient's family to recommend physical modifications in the home and begin preparing the family for the patient's return. The nurse refers the patient at an appropriate time to a rehabilitation counselor assigned by the Department of Rehabilitation to the project. The project helps the patient and the family locate and utilize services available in the community that might resolve particular problems. The project supervises the medical regime and the nursing care for about three months after the patient is discharged from the hospital. The project has also set up a self-help group which provides to individual patients insights into the disability and information about resources which might not otherwise be available through the project. Another program providing similar services operates through a special project at Sharp Memorial Hospital in San Diego. A team made up of a discharge coordinator who is a registered nurse, a therapeutic dietician, a public health nurse from the County Department of Public Health, and a rehabilitation counselor comprise the project staff.

RECOMMENDATION

10. THE DEPARTMENT OF HEALTH SHOULD STUDY THE HOME AND HOSPITAL PROGRAMS OFFERED THROUGH SUCH PROJECTS AS THOSE DESCRIBED ABOVE IN SAN FRANCISCO AND SAN DIEGO AND THEN SERIOUSLY CONSIDER SPONSORING STATE LEGISLATION THAT WOULD APPROPRIATE FUNDS IN SUPPORT OF A STATEWIDE PROGRAM PROVIDING SUCH PROGRAMS TO CARDIAC PATIENTS AND OTHERS WITH CATASTROPHIC OR CHRONIC ILLNESSES. THE DEPARTMENT OF HEALTH MIGHT ALSO PROVIDE ASSISTANCE TO LOCAL COMMUNITIES IN APPLYING FOR FUNDS THROUGH THE AMERICAN HEART ASSOCIATION WHICH MIGHT SUPPORT ADDITIONAL SPECIAL PROJECTS OF THIS KIND.

SELF-HELP GROUPS
CARDIAC DISABILITIES

ISSUE

It can be safely assumed that there are many aspects of cardiac disability that are best understood by the cardiac patient himself. Wherever there have been experiments with organizations of cardiac patients into self-help groups, such as the group developed through the San Francisco Heart Association, they have been found to be of great value from several standpoints.

DISCUSSION

Considerable therapeutic value results from cardiac patients helping and being helped by each other. Moreover, the therapy is of a kind which cannot be provided in any other way. Such groups can also assume an advocacy role which would provide a more unified and organized voice to promote changes that would better meet the needs of the cardiac patient. Such groups might influence the way in which treatment and services are provided in hospitals and in the community, and they might also influence federal and state legislatures which enact laws that affect the person with a cardiac disability.

RECOMMENDATION

11. THE DEPARTMENT OF HEALTH SHOULD ENDORSE DEVELOPMENT OF SELF-HELP ORGANIZATIONS OF CARDIAC PATIENTS AND RECOMMEND TO THE AMERICAN HEART ASSOCIATION, THE DEPARTMENT OF HEALTH, EDUCATION AND WELFARE AND OTHER POSSIBLE SOURCES OF FUNDING THAT SUCH ORGANIZATIONS BE GIVEN HIGH PRIORITY FOR PROJECT MONIES.

PATIENTS AS PAID MEMBERS OF REHABILITATION TEAM
CARDIAC DISABILITIES

ISSUE

Just as self-help groups of cardiac patients have been very effective, use of ex-cardiac patients as members of the cardiac rehabilitation team to serve as counselors of cardiac patients has also proved to be of great value.

DISCUSSION

Local heart associations have already had considerable experience through the "mended hearts" with use of ex-patients as counselors. Many cardiac rehabilitation centers have attempted to utilize the services of ex-patients on a voluntary basis, but they have usually been unable to officially employ ex-patients because the service they provide is not recognized as a professional service which can be reimbursed on a fee-for-service basis.

RECOMMENDATION

12. THE DEPARTMENT OF HEALTH SHOULD WORK WITH EXISTING CARDIAC REHABILITATION CENTERS IN AN EFFORT TO ASSESS THE VALUE OF THE USE OF PATIENTS AS COUNSELORS AND TO BEGIN TO SET STANDARDS FOR THEIR USE ON A FEE-FOR-SERVICE BASIS.

THE COST OF HIRING A DISABLED PERSON
CARDIAC DISABILITIES

ISSUE

There is a great deal of confusion over the question as to whether or not a disabled person costs an employer more for both Workmen's Compensation and health insurance than does the person who is not disabled.

DISCUSSION

Many employers and insurance carriers contend that, across-the-board, the disabled person does cost more. Those in the helping occupations who serve the disabled and attempt to place them in employment cite studies which demonstrate that the disabled person as a worker does not result in higher insurance costs for the employer. The resolution of this controversy would be beneficial to the cause of the disabled.

RECOMMENDATION

13. THE DEPARTMENT OF REHABILITATION SHOULD URGE THE REHABILITATION SERVICES ADMINISTRATION TO FINANCE AN OBJECTIVE RESEARCH PROJECT THAT WOULD SETTLE THE QUESTION OF THE RELATIVE COSTS IN TERMS OF WORKMEN'S COMPENSATION AND HEALTH INSURANCE OF THE EMPLOYMENT OF A DISABLED PERSON AS COMPARED TO ONE WHO IS NOT DISABLED. SUCH A STUDY SHOULD TRY TO ANSWER THIS QUESTION FIRST FOR ALL SIGNIFICANTLY DISABLED PEOPLE AND THEN FOR SEPARATE MAJOR DISABILITY GROUPS SUCH AS THE PERSON WITH A CARDIAC DISABILITY.1/ THE STUDY SHOULD BE CONDUCTED IN SUCH A WAY AS TO YIELD EVIDENCE CONVINCING TO EMPLOYERS AND INSURANCE CARRIERS ON ONE HAND AND DISABLED PERSONS AND THOSE ATTEMPTING TO HELP THEM ENTER OR REENTER THE LABOR MARKET ON THE OTHER. WHATEVER THE RESULTS OF SUCH A STUDY MIGHT BE, THEY SHOULD BE BROADLY PUBLICIZED AND GIVEN OFFICIAL RECOGNITION SO AS TO REPRESENT A FIRM POINT OF REFERENCE IN FUTURE ATTEMPTS TO PLACE THE DISABLED. SUCH A STUDY MIGHT FORM THE BASIS AS WELL FOR FUTURE LEGISLATION WHICH WOULD FACILITATE EMPLOYMENT OF THE DISABLED.

1/ Excellent background material for such a study would be the report on the "Symposium of the Heart in Industry," which was held in Boston on November 9-10, 1967 and sponsored by Tufts University School of Medicine in cooperation with the Massachusetts Heart Association, Inc.

WORKMEN'S COMPENSATION AND REHABILITATION
CARDIAC DISABILITIES

ISSUE

Workmen's Compensation laws had rehabilitation as an important goal at the outset. However, a very small percentage of Workmen's Compensation monies are spent for the rehabilitation of the injured worker.

DISCUSSION

The implementation of Workmen's Compensation laws has resulted in the institutionalization over the years of an adversary system in which employers and insurance carriers are pitted against injured workers in a process of costly litigation. This system does little to encourage rehabilitation. A cardiac patient who feels that a heart condition arises out of and occurs in the course of employment almost always faces litigation in any claim for Workmen's Compensation, since there is some division of professional opinion on whether or not work causes or aggravates heart conditions.

Another problem which discourages rehabilitation of the industrially injured is the fact that successful rehabilitation usually decreases the amount of permanent disability awarded to the injured worker. As such, attorneys representing workers, who base their fees on a percentage of the permanent disability award, have no incentive to counsel their clients toward rehabilitation.

Moreover, the present Workmen's Compensation system offers no incentive to employers to hire persons with heart problems. If an employee develops a heart condition and files a claim that it is work-incurred, the employer will be held fully responsible for any awards made, whether the employee has a history of heart disease or not. Naturally, most employers will assume, with some basis in fact, that ex-cardiacs will be more prone to future heart disease, and they are reluctant to hire them.

RECOMMENDATIONS

14. THE DEPARTMENTS OF REHABILITATION, HEALTH AND INDUSTRIAL RELATIONS SHOULD JOINTLY SPONSOR A TASK FORCE TO STUDY WHETHER OR NOT WORK CAUSES OR AGGRAVATES INDUSTRIAL HEART CONDITIONS, TO DEVELOP GUIDELINES FOR DETERMINATION OF DISPUTES AS TO WHETHER OR NOT HEART CONDITIONS ARE WORK-INCURRED, AND THEN TO PROPOSE TO THE LEGISLATURE, WITH THE ENDORSEMENT OF THE THREE DEPARTMENTS, CHANGES IN THE LABOR CODE REFLECTING SUCH GUIDELINES.1/ IF CLEAR GUIDELINES CANNOT BE DEVELOPED, THE TASK FORCE SHOULD CONCLUDE WHETHER OR NOT ALL HEART CONDITIONS SHOULD BE COMPENSABLE UNDER WORKMEN'S COMPENSATION, OR WHETHER NONE SHOULD BE COMPENSABLE, URGING THE LEGISLATURE TO CHANGE THE LABOR CODE REFLECTING THIS CONCLUSION.

    THE DEPARTMENTS OF REHABILITATION AND INDUSTRIAL RELATIONS SHOULD SPONSOR LEGISLATION THAT WOULD CHANGE THE LABOR CODE FROM THE PRESENT SCHEDULED SYSTEM OF RATING PERMANENT DISABILITY TO A WAGE-LOSS SYSTEM.

1/ Here again the report on the "Symposium of the Heart in Industry", Boston, November 9-10, 1967, sponsored by Tufts University School of Medicine in cooperation with the Massachusetts Heart Association, Inc., would be most useful as a basis for starting such a study.

15. THE DEPARTMENT OF REHABILITATION SHOULD ASSUME RESPONSIBILITY FOR EDUCATING EMPLOYERS THAT RETURNING TO WORK AFTER A HEART ATTACK IS NOT PARTICULARLY DANGEROUS AND THAT THE UNREHABILITATED CARDIAC PATIENT CAN BECOME A COSTLY BURDEN TO THE FAMILY AND THE COMMUNITY. THIS MIGHT BE CARRIED OUT IN A NUMBER OF WAYS, INCLUDING THE DEVELOPMENT OF A SPECIAL BROCHURE TO BE USED IN THE PLACEMENT OF CARDIAC REHABILITATION CLIENTS.

PRIVATE INSURANCE CARRIERS AND CARDIAC REHABILITATION
CARDIAC DISABILITIES

ISSUE

Although many general health insurance policies contain a clause which makes rehabilitation mandatory, many insurance carriers do not really appreciate the value of rehabilitation and, even when they do, there are at the present time few recognized standards for those who call themselves rehabilitation counselors.

RECOMMENDATIONS

16. THE DEPARTMENT OF REHABILITATION AND PROFESSIONAL ORGANIZATIONS AMONG THE ALLIED HEALTH DISCIPLINES SHOULD ENCOURAGE AND ENDORSE EFFORTS TO CERTIFY OR LICENSE REHABILITATION COUNSELORS, SUCH AS THOSE PRESENTLY BEING CARRIED OUT BY THE NATIONAL REHABILITATION COUNSELORS ASSOCIATION OF THE NATIONAL REHABILITATION ASSOCIATION.

17. THE DEPARTMENT OF REHABILITATION SHOULD SPONSOR MEETINGS INVOLVING PHYSICIANS, OTHER QUALIFIED EXPERTS IN REHABILITATION, INSURANCE UNDERWRITERS AND CLAIMS REPRESENTATIVES FOR AN EXCHANGE OF IDEAS THAT WOULD INCREASE THE KNOWLEDGE OF INSURANCE CARRIERS OF THE ADVANTAGES OF REHABILITATION.

AN ANNOTATED LIST OF POSITION PAPERS
AND OTHER RESOURCE MATERIAL
CARDIAC DISABILITIES

1. Hollister, Kathryn. "An Overview of the San Francisco Heart Association Project".
   A description of a special project which provides a program of hospital and nursing services to cardiac patients from six hospitals in San Francisco. The project begins one week after the patient's admission with education on matters such as physiology, exercise, diet, medications, sexual activity and risk factors; provides orientation and counseling to the family prior to discharge; and continues providing supervision of the medical regime and nursing services three months post-discharge.

2. Ito, Isamu "Sam". "Consumer Viewpoint by a Cardiac Patient".
   A letter from an ex-cardiac patient to co-members of the Cardiac Study Group, which describes his firsthand experience as a patient in the hospital before and after surgery, as a debt-ridden, frightened and depressed person when he could not find work, and as a grateful ex-cardiac finally on the road to recovery and rehabilitation.

3. Matheson, Leonard N. and Ito, Isamu "Sam". "Psychological Aspects of Cardiac Disability - A Dialogue".
   An outline of a dialogue between a clinical psychologist and a cardiac patient who was also a Department of Rehabilitation client. The patient relates his personal perspective on his motivation for medical rehabilitation, his response to medical rehabilitation, his attempts to return to work, his application for Social Security Disability benefits, his experience with the rehabilitation counselor, his program of psychotherapy and finally his return to work. The psychologist reflects upon each step of the patient's experience and feelings from the standpoint of a clinical psychologist who has had experience with several hundred patients in a large cardiac rehabilitation program.

4. Matheson, Leonard N., M.A, Sylvester, Ronald H., M.D.; Rice, Harry E., M.D.
   A research paper which explains the difference between cardiac restoration and cardiac rehabilitation, traces and evaluation and treatment program operating at Rancho Los Amigos Hospital, and describes the model used for an inter-disciplinary cardiac rehabilitation team. The paper then describes in some detail the roles played by individual team members: the physician, the nursing team, the occupational therapist, the physical therapist, the nutritionist, the liaison nurse, the medical social worker, the clinical psychologist, the prevocational counselor and the recreational therapist. The paper also contains an extensive bibliography of articles and papers on the rehabilitation of the cardiac patient.

5. Reese, Richard D., Ph.D. "Unmet Needs in Hospitals and Rehabilitation Centers".
   This paper interprets and reports on the results of a coronary rehabilitation questionnaire conducted by the Cardiac Study Group. The survey shows that whereas a variety of services are available through California hospitals, they are difficult to coordinate and both inpatient and outpatient services are underutilized. The survey points out that although there is a lack of comprehensive coronary rehabilitation programs in California, respondents to the questionnaire expressed considerable interest in the development of more of such programs.

6. Smith, Bryant. "Social and Vocational Implications of Recreational Therapy of Cardiac Rehabilitation".
   A paper by an ex-cardiac patient who is now a recreation therapist in the cardiac rehabilitation program at Rancho Los Amigos Hospital. The paper explains that recreational therapy seeks not just to provide activity for a patient's extra time, but to help develop and maintain in the patient a sense of self-worth. Relating a case history, Mr. Smith shows how one patient moves from a state of worry and depression to discovery of a talent for oil painting and finally to active leadership of a project of the Cardiac Patient's Association.

7. Williams, Dale. "Social and Vocational Aspects of Cardiac Rehabilitation".
   A description of the team approach used by the Heart Project at Sharpe Memorial Hospital in San Diego. Project services may begin even prior to hospital admission and continue after discharge in the home or community until such time as community resources or the patient's own resources put the patient on the road to total rehabilitation. Services include comprehensive discharge planning, dietary counseling, home nursing which provides continuing liaison between the hospital physician and the patient and his family, and evaluation and rehabilitation counseling in the personal, financial, vocational and avocational areas.

8. Zelco, James. "Cardiac Disability and Insurance". A brief review of the history and philosophy behind Workmen's Compensation laws, followed by a discussion of the ways current laws, the adversary system and the lack of employer incentive stand in the way of rehabilitation of the cardiac patient. The paper notes some improvements in the system with the passage of AB 760, but suggests that further amendments to the Labor Code may be needed to resolve remaining problems with it. The paper also points out that most general health insurance policies have clauses on rehabilitation which are never implemented because the art and science of rehabilitation is not legally standardized.

HIGH COSTS OF TREATMENT OF SEVERE RENAL DISEASE
RENAL DISABILITIES

ISSUE

The costs for the treatment of severe renal disease are extremely high and compound the disability of the renal patient.

DISCUSSION

In spite of the high costs of treatment of renal disease, Medicare and most private insurance policies cover only 80% of the treatment. Medi-Cal does help in the payment of the additional 20%, but by what renal patients call the "no work law" they must reimbruse Medi-Cal for this on a dollar-for-dollar basis from any earnings they make. Twenty percent of the cost of hemodialysis alone can run as high as $100 per week. What this situation does is to add to the renal patient's already serious disease the new social diseases of dependency and economic deprivation. If the health care system relieved the patient of this financial burden, the higher short-run costs would be indirectly offset in the long-run by the taxes paid by the patient from earnings in employment.

RECOMMENDATION

18. THE DEPARTMENT OF HEALTH SHOULD CONSIDER FULL PAYMENT OF TREATMENT FOR THE RENAL PATIENT. IF IT IS FIRST NECESSARY TO DEMONSTRATE THE COMPARATIVE COST EFFECTIVENESS OF FULL PAYMENT WITH 80% PAYMENT, THE DEPARTMENT SHOULD SUPPORT A LONG-TERM RESEARCH PROJECT THAT WOULD STUDY THE MATTER AND THEN WORK TO CHANGE LAWS, REGULATIONS OR POLICIES TO CONFORM WITH THE FINDINGS OF SUCH A PROJECT.

ISSUE

What renal patients refer to as the "no work law" traps the patient in a state of economic dependency or strongly encourages the working victim of renal disease to commit fraud by not reporting earnings.

RECOMMENDATION

THE DEPARTMENT OF HEALTH SHOULD PROMOTE CHANGES IN LAW, REGULATIONS, AND POLICY TO REMOVE THE REQUIREMENTS THAT THE WORKING RENAL PATIENT REIMBURSE MEDI-CAL FOR PAYMENT OF 20% OF THE COSTS OF TREATMENT OUT OF ANY INCOME EARNED.

DIALYSIS HOURS IN HEMODIALYSIS CENTERS
RENAL DISABILITIES

ISSUE

Most hemodialysis centers provide dialysis during the day, that is, during the hours during which most people work. This is another condition which stands in the way of employment for renal patients.

DISCUSSION

Daytime dialysis hours may meet the incidental needs of the average hospital, but they ignore the rather critical needs of many renal patients to work. Daytime dialysis hours are another example like the "no work law" of rather arbitrary policies which stand in the way of the true vocational rehabilitation of the patient or the renal patient. Most hospitals and hemodialysis centers would be able to provide nighttime dialysis to the working renal patient at little or no additional cost.

RECOMMENDATION

19. THE DEPARTMENT OF REHABILITATION AND THE DEPARTMENT OF HEALTH SHOULD STRONGLY URGE HOSPITALS AND HEMODIALYSIS CENTERS TO MAKE DIALYSIS AVAILABLE DURING NIGHT HOURS FOR ANY RENAL PATIENTS WHO ARE WORKING. MOREOVER, DIALYSIS CENTERS SHOULD INFORM PATIENTS OF THE AVAILABILITY OF NIGHTTIME DIALYSIS SO THAT AS PART OF THEIR REHABILITATION PROGRAM THEY REALIZE THAT EMPLOYMENT MAY BE FEASIBLE FOR THEM.

SELF-HELP ORGANIZATIONS
RENAL DISABILITIES

ISSUE

Renal patients themselves often know more about some aspects of their disease than do the professionals attempting to serve them. Self-help organizations would not only alleviate many practical problems for the renal patient, they would also have a very beneficial therapeutic effect.

DISCUSSION

Here and there, self-help organizations of renal patients have sprung up spontaneously. They have demonstrated that they can be quite effective in the promotion of better patient care and in correction of many practical problems encountered by the renal patient. One good example of such a self-help organization is the non-profit corporation run by renal patients at USC County General Hospital. Such organizations strengthen cohesiveness among patients, give them a strong voice by which they can lobby for change both within the hospital setting and within national and state legislative bodies. The group dynamics involved in such self-help organizations has a positive therapeutic effect upon the individual renal patient. Such organizations can also serve as information and education centers for victims of renal disease.

RECOMMENDATION

20. THE DEPARTMENT OF REHABILITATION SHOULD EXPLORE SOURCES OF FUNDING, INCLUDING FUNDING THROUGH THE REHABILITATION SERVICES ADMINISTRATION, TO FINANCE THE ESTABLISHMENT OF CONSUMER ADVOCATE GROUPS. THREE MODEL SELF-HELP ORGANIZATIONS SIMILAR TO THE ONE OPERATING AT USC COUNTY GENERAL HOSPITAL SHOULD BE SET UP IN CALIFORNIA.

THE EMPLOYABILITY OF RENAL PATIENTS
RENAL DISABILITIES

ISSUE

In spite of the functional limitations resulting from severe renal disease and the bureaucratic barriers that make employment difficult, the renal patient can work.

DISCUSSION

The Department of Rehabilitation has already had in-depth experience in the rehabilitation of victims of severe kidney disease through its program at USC County General Hospital. The Department knows through this effort that the renal patient can work. There is throughout the Department, however, a lack of understanding of the problems faced by the renal patient and of the kinds of support services needed in order to enter employment. Employers will not begin to acknowledge the work potential of renal patients until all staff in the Department of Rehabilitation understands the problems of the renal patient and becomes familiar with the kinds of support services needed by the renal patient in order to enter employment.

RECOMMENDATION

21. THE DEPARTMENT OF REHABILITATION SHOULD STUDY WHATEVER EXPERIENCE IT HAS HAD IN THE REHABILITATION OF RENAL PATIENTS, EDUCATE ITS STAFF IN GENERAL ON THE PROBLEMS OF THE RENAL PATIENT AND ON THE TECHNIQUES AND SERVICES REQUIRED FOR VOCATIONAL REHABILITATION. THEN, KNOWING THAT THERE ARE MANY RENAL PATIENTS WHO CAN WORK, REHABILITATION COUNSELORS THROUGHOUT THE STATE SHOULD BEGIN TO EDUCATE EMPLOYERS ON THE WORK POTENTIAL OF THE RENAL PATIENT AND PROVIDE ANY PLACEMENT SERVICES NECESSARY TO HELP THE RENAL PATIENT ENTER AND MAINTAIN EMPLOYMENT.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE AS A REHABILITATION PRIORITY
RESPIRATORY DISABILITIES

ISSUE

Chronic obstructive pulmonary disease represents the most rapidly increasing disability in the country, but ranks relatively low as a national priority.

DISCUSSION

Respiratory diseases represent a major cause of death and disability. Each year respiratory patients enter the ranks of the disabled at a greater rate than any other single disability group. Moreover, chronic obstructive pulmonary disease costs the nation 6.5 billion dollars per year. Estimates put direct costs at 1.7 billion dollars, indirect costs at 1.6 billion, and indirect mortality costs at 3.2 billion. Such costs could be reduced and the rate of death and disability significantly slowed down by a broader application of already known techniques for the rehabilitation of the respiratory patient.

RECOMMENDATION

22. THE DEPARTMENT OF REHABILITATION SHOULD PUT THE VICTIM OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE HIGH ON ITS PRIORITY LIST FOR THE UTILIZATION OF VOCATIONAL REHABILITATION RESOURCES JUST AS THE DEPARTMENT OF HEALTH SHOULD ASSIGN TO RESPIRATORY PATIENTS HIGH PRIORITY FOR THE UTILIZATION OF HEALTH CARE RESOURCES.

COMPREHENSIVE RESPIRATORY REHABILITATION PROGRAMS
RESPIRATORY DISABILITIES

ISSUE

California should establish more comprehensive respiratory rehabilitation centers and make a stronger effort to coordinate statewide those centers now in existence.

DISCUSSION

To be comprehensive a respiratory rehabilitation center must use an integrated team approach to both the medical and nonmedical needs of respiratory patients prior to, during and following hospitalization. A comprehensive program would include diagnosis and evaluation of the patient, his work, his disability, his home situation and other factors; an adequate medical therapy program; a patient education program on the disease process and on preventative measures; physical reconditioning as well as other physical maneuvers; psychological evaluation and support; social services, including any homemaker services required; occupational therapy; and adequate patient follow up. As in the case of the cardiac patient, the emphasis is on rehabilitation, not just restoration. The patient must understand his disease process, learn how to prevent respiratory distress, and become as independent as possible. The team approach involves many disciplines working together, their actions contributing consistently to overall rehabilitation goals set for the individual patient. Such a team should include at a minimum physicians, nurses, respiratory therapists, chest physical therapists, psychologists, social workers, occupational therapists and consumers. Many communities do not have adequate trained personnel to make up such a team. Many communities that do have a variety of disciplines functioning fail to organize their efforts into a comprehensive program.

The study group conducted a survey showing that many communities lack adequate respiratory rehabilitation programs.

RECOMMENDATION

23. THE DEPARTMENT OF HEALTH AND DEPARTMENT OF REHABILITATION SHOULD MAKE A THOROUGH STUDY TO IDENTIFY COMPREHENSIVE RESPIRATORY REHABILITATION CENTERS THAT MEET THE DESCRIPTION GIVEN ABOVE. SUCH A STUDY SHOULD DETERMINE THE EXTENT OF THE NEED FOR ADDITIONAL CENTERS AND THEN THE DEPARTMENTS SHOULD EXPLORE STATE AND FEDERAL SOURCES OF FUNDING FOR THE ESTABLISHMENT OF ADDITIONAL CENTERS.

ISSUE

Some of the need for comprehensive centers might be met by better coordination of existing resources in many communities.

RECOMMENDATIONS

24. THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD, WITH THE ASSISTANCE OF DIRECTORS OF ALREADY ESTABLISHED COMPREHENSIVE RESPIRATORY REHABILITATION CENTERS, MEET WITH MEDICAL DIRECTORS, HOSPITAL ADMINISTRATORS AND REPRESENTATIVES OF OTHER MEDICAL AND PARAMEDICAL PROFESSIONS TO EXPLORE WAYS IN WHICH IMPROVED COORDINATION OF A VARIETY OF DISCIPLINES COMMITTED TO THE TEAM APPROACH TO REHABILITATION CAN BE CARRIED OUT.

25. THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD LEND SUPPORT TO ANY STATE OR FEDERAL APPROPRIATIONS OF FUNDS INTENDED TO INCREASE THE NUMBER OF TRAINED MEDICAL AND PARAMEDICAL PROFESSIONALS GRADUATING FROM COLLEGES AND UNIVERSITIES.

26. THE DEPARTMENTS OF REHABILITATION, HEALTH AND EDUCATION SHOULD CONSULT WITH DIRECTORS OF ESTABLISHED COMPREHENSIVE RESPIRATORY REHABILITATION CENTERS AND THEN ATTEMPT TO INFLUENCE THE CURRICULA OF MEDICAL SCHOOLS, RESIDENTIAL TRAINING PROGRAMS OF TEACHING HOSPITALS, AND THE CURRICULA OF THE VARIOUS PARAMEDICAL DISCIPLINES AS A MEANS OF PROMOTING A COMPREHENSIVE INTER-DISCIPLINARY REHABILITATION TEAM APPROACH TO THE TREATMENT OF RESPIRATORY PATIENTS.

ADEQUATE REIMBURSEMENT FOR COMPREHENSIVE RESPIRATORY REHABILITATION SERVICES RESPIRATORY DISABILITIES

ISSUE

The development of comprehensive respiratory rehabilitation centers and of trained personnel to staff them has been retarded by the fact that private insurance and public health care programs frequently fail to adequately reimburse the centers for comprehensive services.

DISCUSSION

Most insurance and health care programs cover most of the cost of acute care, but they are often reluctant to pay for such things as in-hospital rehabilitation care, outpatient treatment, home use respirators, drugs, etc. Costs for outpatient treatment can run as high as $200 to $300 per month, while drugs can vary in cost from $25 to $225 per month. In addition, respiratory patients must pay 20% of the cost of home use respirators. Often patients who should be under regular care visit their doctors infrequently due to the high cost of transportation.

The costs of health care are quite high. Private insurance carriers and public health care programs have a legitimate need to keep medical costs down. Nevertheless, they should recognize that failure to provide adequate rehabilitation services to the respiratory patient will result in higher overall costs in the long-run. At the same time, rehabilitation centers should recognize the need to keep the costs of rehabilitation programs reasonable and auditable.

RECOMMENDATIONS

27. THE DEPARTMENT OF HEALTH SHOULD BEGIN TO CONSULT WITH REHABILITATION CENTERS WITH THE AIM OF DEVELOPING WORKABLE FEE SCHEDULES FOR COMPREHENSIVE, INTERDISCIPLINARY REHABILITATION SERVICES TO RESPIRATORY PATIENTS. IF THE DEPARTMENT OF HEALTH DOES NOT ACCEPT THE PREMISE THAT COMPREHENSIVE SERVICES ARE LESS COSTLY IN THE LONG RUN, IT SHOULD SUPPORT FUNDING FOR A RESEARCH PROJECT WHICH WOULD COMPARE THE RELATIVE LONG-TERM COST EFFECTIVENESS OF TREATMENT THROUGH AN INTERDISCIPLINARY TEAM ON THE ONE HAND AND A PHYSICIAN IN A PRIVATE SETTING ON THE OTHER. THE FINDINGS OF SUCH A PROJECT MIGHT FORM THE BASIS FOR ESTABLISHING A FEE SCHEDULE FOR COMPREHENSIVE SERVICES.

28. ONCE MEDI-CAL DEVELOPS WORKABLE PROCEDURES FOR DEFINING COMPREHENSIVE, INTERDISCIPLINARY REHABILITATION SERVICES ON A FEE-FOR-SERVICE BASIS, BOTH THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD PROMOTE LEGISLATIVE CHANGES IN THE INSURANCE AND LABOR CODES WHICH WOULD REQUIRE PAYMENT FOR ADEQUATELY JUSTIFIED REAHBILITATION SERVICES.

29. UNTIL SUCH TIME AS WORKABLE PROCEDURES ARE DEVELOPED BY MEDI-CAL AND PRIVATE INSURANCE CARRIERS FOR PAYMENT FOR COMPREHENSIVE REHABILITATION SERVICES, THE DEPARTMENT OF REHABILITATION SHOULD, AS A MATTER OF POLICY, ASSUME PAYMENT FOR SUCH SERVICES WITHIN ITS RESOURCES FOR REHABILITATION CLIENTS WHO ARE RESPIRATORY PATIENTS.

MENTAL DISABILITIES
OVERVIEW

PRECONFERENCE STUDY GROUP

The Mental Disabilities Study Group consisted of professionals from public and private mental health service providers, the Department of Health, the Department of Rehabilitation, the Mental Health Association and consumers. Throughout the summer, the committee met on a regular basis in an effort to map a study for the identification of unmet needs of the mentally disabled in California. Because of the short time before the conference, a questionnaire method of study was chosen. It was decided that a questionnaire would be devised to go to mental health providers, to consumers of mental health services and one to rehabilitation counselors. Final tabulations and recommendations from these questionnaires are summarized below.

SUMMARY OF STUDY RESULTS

Availability and adequacy of rehabilitation services for the mentally disabled, reasons for service denials, and needed service improvements were investigated in a 1974 questionnaire survey which gathered information from not-necessarily-representative samples of California providers and consumers of such services. Consumers reported that 71% of their needed or requested services were both received and found satisfactory. Providers, however, regarded only 52% of their clients' needs as having been satisfactorily met. This 19% overall consumer-provider difference was exceeded for four specific services -- housing, financial assistance, mental health and medical -- but the two groups agreed closely on the receipt and adequacy of educational services and vocational counseling or training. Consumers and providers agreed that of six specific services, the two most often provided satisfactorily when needed are medical and mental health services. The consumers' high-to-low ranking of the other services were housing, financial assistance, vocational counseling/training and educational services. The providers inverted that order.

When respondents were asked to identify which of four reasons accounted for failure to receive specified services, "services not available" was the highest ranking reason in both groups, with consumers selecting it for 58% of service denials and providers for 42%. The consumer and provider percentages for the other three reasons were: "condition too severe", 20% and 18% respectively; "condition not severe enough", 12% and 26% respectively; and "other reasons" 10% and 14% respectively. Among providers, the reasons most frequently given for failures to receive specific services were "not available" for housing and financial assistance, "condition not severe enough" for mental health and medical services, and "condition too severe" for educational services and vocational counseling or training. No comparable statement was available for the consumers because of their low responsiveness to the item.

More service improvement needs were noted by providers than by consumers. The groups' combined responses to a ten-item list ranked red tape and delays at the top of the improvement-needed list, and characteristics of received services (i.e., provider attitudes, service quality, service cost and "other" improvements) at the bottom of the list. Intermediate were attitudes of the general

public, availability of specialized services, information about services and cooperation and communication. Responses to open-ended questions about needed improvements were consistent with these rankings.

STUDY GROUP RECOMMENDATIONS

After a review of the results of the questionnaire, the study committee planned the mental disabilities section of the conference. The primary issues identified through the questionnaires were to be brought to the mental disabilities section for open discussion and recommendations. The primary issues identified were as follows:

1. Training
2. A signed rehabilitation plan
3. More staff needed
4. Public education
5. Consumer and provider involvement in planning
6. Employment
7. Work activity centers
8. Multipurpose centers
9. Coordination of services
10. Advocacy
11. Assembly Bill 1126

CONFERENCE OVERVIEW

The general feeling of the conference was described by numerous participants as open, moving, meaningful, and hopeful. Many other positive adjectives were used. It was the general agreement that unless something can come of the many good feelings and recommendations it will be a great disappointment to many. The mental disabilities section was much larger than had been anticipated. While small buzz groups were planned with group leaders, the groups were frequently too large for small group participation. In spite of this, the discussions were fruitful and identified a number of issues and recommendations.

TRAINING
MENTAL DISABILITIES

ISSUE

The Health and Welfare Agency should require its departments to develop in-service and out-service training plans for those employees providing services to the mentally disabled.

DISCUSSION

Consumers and providers of rehabilitation services often complain that mental health workers and counselors do not convey a sincere and helping attitude. A common reason given is lack of adequately trained mental health professionals.

RECOMMENDATIONS

30. THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION SHOULD BOTH HAVE AN IN-SERVICE AND OUT-SERVICE TRAINING PROGRAM FOR THOSE WORKERS PROVIDING SERVICES TO THE MENTALLY DISABLED.

31. AFTER CONSULTATION WITH CONSUMERS AND PROVIDERS THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION SHOULD FORMULATE A WRITTEN PLAN. THIS PLAN SHOULD BE A JOINT PLAN AND INDICATE THE LEGAL RESPONSIBILITIES AND SPECIAL ROLES OF EACH DEPARTMENT. CONSULTATION FROM COMMUNITY MENTAL HEALTH AGENCIES, BOTH PUBLIC AND PRIVATE, SHOULD BE OBTAINED BEFORE PLAN IMPLEMENTATION. THE PLAN SHOULD CONTAIN A MECHANISM FOR ANNUAL UPGRADING.

32. MENTAL HEALTH PROGRAM MANAGERS IN THE DEPARTMENTS OF HEALTH AND REHABILITATION SHOULD BE RESPONSIBLE FOR INFORMATION SHARING WITH OTHER AGENCIES OR DEPARTMENTS SERVING THE MENTALLY ILL.

33. REHABILITATION FACILITIES SERVING THE MENTALLY DISABLED SHOULD HAVE APPROVAL TO SEND THEIR STAFF TO IN-SERVICE PROGRAMS CONDUCTED BY AGENCIES OR DEPARTMENTS. THE DEPARTMENTS OF REHABILITATION AND HEALTH SHOULD ENCOURAGE STATE EMPLOYEES TO PARTICIPATE IN TRAINING PROGRAMS SPONSORED BY COMMUNITY MENTAL HEALTH AGENCIES AND REHABILITATION FACILITIES.

A SIGNED REHABILITATION PLAN
MENTAL DISABILITIES

ISSUE

Consumers and providers feel that clients are often placed in a rehabilitation plan not knowing the full details. When this happens, clients and those professionals attempting to provide service feel defeated and frustrated. A client's failure to benefit from services often leads to further personal, social, and economic disorganization.

DISCUSSION

The rehabilitation plan should include all agencies concerned with the client's welfare and outline the legal responsibilities agencies have for the client's rehabilitation. This is a matter of good casework and is usually done by the worker who has had adequate training and proper supervision. However, the mentally disabled are often involved with various social agencies and some workers may not have a clear understanding of who has responsibility in a given situation. When this happens, the client's rehabilitation plan becomes fragmented and plans of action go astray.

RECOMMENDATION

34. ALL CLIENTS OF THE DEPARTMENT OF REHABILITATION SHOULD REVIEW PLANNED SERVICES WITH THEIR COUNSELOR. CLIENTS SHOULD INITIAL THIS PLAN AS INDICATING THEIR APPROVAL AND COMMITMENT TO THE PLAN OF ACTION. IF THE CLIENT IS RECEIVING MAJOR SERVICES FROM OTHER SOCIAL AGENCIES, THE COUNSELOR AND THE CLIENT SHOULD MEET WITH THAT AGENCY'S WORKER TO ENSURE THAT A DUPLICATION OF SERVICES DOES NOT EXIST AND PLANS OF ACTION ARE NOT IN CONFLICT. CONFLICTS IN LEGAL RESPONSIBILITIES OR PLANS OF ACTION SHOULD BE RESOLVED WITH THE CLIENT IF POSSIBLE.

MORE STAFF NEEDED
MENTAL DISABILITIES

ISSUE

More paraprofessionals and volunteers should be working with the mentally disabled. There should be a coordinated program to locate and screen lay persons who have an interest and the ability to work with the mentally disabled. While efforts of this type are currently being carried out by local mental health associations and social service clubs, efforts are often fragmented and fail to serve those people most in need. Also, coordination between state departments having a legal responsibility for serving the mentally disabled and the private agencies needs improvement in most cases.

RECOMMENDATION

35. THE DEPARTMENT OF REHABILITATION AND THE DEPARTMENT OF HEALTH SHOULD INVESTIGATE THE FEASIBILITY OF INITIATING A PILOT PROGRAM USING VOLUNTEERS AS CASE AIDES. THE CALIFORNIA ASSOCIATION FOR MENTAL HEALTH, CALARF, AND COUNTY MENTAL HEALTH ASSOCIATIONS SHOULD BE ASKED TO PARTICIPATE IN THIS FEASIBILITY STUDY.

PUBLIC EDUCATION
MENTAL DISABILITIES

ISSUE

The general public should be better informed about the causes, treatment, and prevention of mental illness. Rehabilitation resources available to the mentally disabled should be discussed.

RECOMMENDATION

36. THE HEALTH AND WELFARE AGENCY SHOULD PRESENT A SERIES OF EDUCATIONAL FILMS DEMONSTRATING THE ROLE OF EACH AGENCY DEPARTMENT. ALL DEPARTMENTS WITHIN THE AGENCY SHOULD PARTICIPATE IN THIS EFFORT. THESE FILMS WOULD BE FREE AND OPEN TO THE PUBLIC. TV SPOTS, RADIO AND ADVERTISING SHOULD BE USED TO ATTRACT AUDIENCES. WHENEVER POSSIBLE, THESE PRESENTATIONS SHOULD BE OFFERED IN SPANISH. THESE FILMS, CASSETTES AND OTHER INFORMATIONAL LITERATURE COULD BE MADE AVAILABLE TO REHABILITATION FACILITIES, COLLEGES, SOCIAL CLUBS, AND OTHER PARTIES INTERESTED IN REHABILITATING THE MENTALLY DISABLED.

CONSUMER AND PROVIDER INVOLVEMENT IN PLANNING MENTAL DISABILITIES

ISSUE

Rehabilitation planning for the mentally disabled should include more input from both consumers and providers.

DISCUSSION

State agencies often initiate special projects and programs for the mentally disabled without adequately determining the need for such programs or consulting target communities. This oversight often leads to program failure right from the start since local communities have had no say in the formulation of the program and feel no accountability for its success.

RECOMMENDATION

37. THE DEPARTMENTS OF HEALTH AND REHABILITATION SHOULD ESTABLISH A CONSUMER/PROVIDER ADVISORY BOARD. SELECTION CRITERIA AND THE NUMBER OF PERSONS TO SERVE ON THIS ADVISORY BOARD WOULD HAVE TO BE DETERMINED. THE MAJORITY OF THIS BODY SHOULD BE CONSUMERS, FORMER CONSUMERS OR PROVIDERS OF MENTAL HEALTH SERVICES. CONSUMERS/PROVIDERS WOULD SERVE ON THIS BOARD WITHOUT PAY. PERHAPS A SMALL OPERATING BUDGET COULD BE PROVIDED BY THE DEPARTMENTS INVOLVED. RECOMMENDATIONS FROM THIS ADVISORY BOARD WOULD BE SHARED WITH STATE DEPARTMENTS AND OTHER CONCERNED AGENCIES PROVIDING REHABILITATION SERVICES TO THE MENTALLY DISABLED.

EMPLOYMENT
MENTAL DISABILITIES

ISSUE

Gainful employment should not be the only criteria for a successful rehabilitation.

RECOMMENDATION

38. THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION LEGAL COUNSEL SHOULD ADVOCATE LEGISLATION THAT WOULD PERMIT CHANGING THE FEDERAL LEGISLATION CONCERNING CRITERIA FOR SUCCESSFUL REHABILITATION. FEDERAL LEGISLATION SHOULD INCLUDE INCREASED SELF-SUFFICIENCY AND THE LEVEL OF FUNCTIONING AS A MEASURE OF SUCCESSFUL CLOSURE. ADEQUATE DOCUMENTATION WOULD HAVE TO BE INCLUDED IN CASE FOLDERS. PERSONS NOT DEMONSTRATING A POTENTIAL FOR EMPLOYMENT SHOULD NOT BE EXCLUDED FROM REHABILITATION SERVICES.

WORK ACTIVITY CENTERS
MENTAL DISABILITIES

ISSUE

There is a need for more work activity centers.

DISCUSSION

Many mentally disabled persons are not able to immediately enter training or competitive workshop situations upon release from a treatment facility. Many of these persons are severely disabled and require a gradual reentry into the world of work. While the California State Plan for Rehabilitation Facilities lists 30 work activity centers statewide, some Department of Rehabilitation districts are shown to have no centers within their geographic boundary.

RECOMMENDATION

39. THE DEPARTMENT OF REHABILITATION FACILITIES SECTION, THE DEPARTMENT OF HEALTH, AND THE CALIFORNIA ASSOCIATION FOR REHABILITATION FACILITIES SHOULD WORK CLOSELY TOGETHER TO DETERMINE THE NEED FOR MORE WORK ACTIVITY CENTERS. WHERE NEED IS FOUND TO EXIST, EXISTING WORKSHOPS SHOULD BE ENCOURAGED TO EXPAND THEIR SERVICES TO INCLUDE MORE PREVOCATIONAL, PERSONAL AND SOCIAL SERVICES PROGRAMS. BOTH DEPARTMENTS SHOULD EXPLORE ALTERNATIVE WAYS OF FUNDING PROGRAMS WHERE RAISING MATCHING MONIES PRESENTS A BARRIER TO ESTABLISHING WORK ACTIVITY CENTERS.

MULTIPURPOSE CENTERS
MENTAL DISABILITIES

ISSUE

The number of mentally disabled residing in the community has increased dramatically over the past several years largely due to the tremendous affect of the Lanterman-Petris-Short Act. It has been difficult for most communities to provide the necessary treatment systems and necessary facilties required by this exodus of mental patients from state hospitals to communities.

DISCUSSION

While communities have provided the mentally disabled with the basic necessities, other needs of the mentally disabled often go unmet. The chronically mentally ill are often forgotten. Most reside in some form of board-and-care or halfway house. Those who are able to live independently very often lead lonely lives with little social interaction. Many are given medication which sedates them into a nontroublesome state, making it easier for caretakers, friends and family to handle.

RECOMMENDATION

40. THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION SHOULD ENCOURAGE LOCAL MENTAL HEALTH AGENCIES TO STUDY THE FEASIBILITY OF ESTABLISHING MORE MULTIPURPOSE CENTERS FOR THE MENTALLY DISABLED. THESE CENTERS SHOULD BE OPEN DAILY. ACTIVITIES WOULD INCLUDE PREVOCATIONAL, PERSONAL AND SOCIAL PROGRAMS ACCORDING TO THE INDIVIDUAL'S ABILITY TO BENEFIT. WORK PROGRAMS SHOULD INCLUDE WORK SAMPLING, EVALUATION AND ADJUSTMENT. THE CENTER MAINTENANCE AND UPKEEP COULD PROVIDE A WIDE RANGE OF REALISTIC WORK SITUATIONS.

41. EACH MULTIPURPOSE CENTER SHOULD BE PROVIDED WITH A VAN TO MEET THE TRANSPORTATION NEEDS OF THOSE UNABLE TO TRAVEL BY PRIVATE CARS OR OTHER PUBLIC TRANSPORTATION. THIS VAN SHOULD BE FUNDED WITH FEDERAL, STATE, AND LOCAL FUNDS.

COORDINATION OF SERVICES
MENTAL DISABILITIES

ISSUE

Agencies providing rehabilitation services to the mentally disabled are often fragmented and need to be better coordinated.

RECOMMENDATIONS

42. A COORDINATOR FOR MENTAL HEALTH PROGRAMS SHOULD BE APPOINTED BY THE HEALTH AND WELFARE AGENCY. THIS LIAISON PERSON SHOULD COMMUNICATE WITH OTHER AGENCIES AND DEPARTMENTS SERVING THE MENTALLY DISABLED. THE COORDINATOR SHOULD ENSURE THAT DEPARTMENTS ARE **NOT** DUPLICATING SERVICES, THAT AREAS OF DEPARTMENTAL RESPONSIBILITY ARE CLEARLY DEFINED, AND WRITTEN PLANS OF ACTION EXIST.

43. THE MAJOR ROLE OF THE HEALTH AND WELFARE AGENCY COORDINATOR SHOULD BE THAT OF A FACILITATOR OF MENTAL HEALTH SERVICES. UPON REQUEST THIS PERSON WOULD ASSIST AGENCY PERSONNEL WORKING WITH THE MENTALLY DISABLED OR ASSIST ANY GROUP IN PREPARING A COORDINATED PLAN WHERE GAPS IN SERVICES APPEAR TO EXIST. THE AGENCY FACILITATOR SHOULD ALSO BE A MEMBER OF THE PROPOSED CONSUMER/PROVIDER ADVISORY BOARD.

ADVOCACY
MENTAL DISABILITIES

ISSUE

There should be a coordinated and cooperative program for client advocacy involving both the public and private sectors of the community.

RECOMMENDATION

44. THE DEPARTMENTS OF HEALTH AND REHABILITATION SHOULD MEET WITH CONSUMER/PROVIDER ORGANIZATIONS REPRESENTED BY ORGANIZATIONS SUCH AS THE CALIFORNIA ASSOCIATION FOR MENTAL HEALTH AND THE CALIFORNIA ASSOCIATION FOR REHABILITATION FACILITIES. THE SPECIAL ADVOCACY NEEDS OF THE MENTALLY DISABLED COULD THEN BE INTERWOVEN WITH AN OVERALL PLAN OF ADVOCACY FOR THE HANDICAPPED THROUGHOUT THE STATE OF CALIFORNIA. THE DEPARTMENT OF REHABILITATION WOULD HAVE THE MAJOR RESPONSIBILITY FOR CARRYING OUT THIS PLAN.

ASSEMBLY BILL 1126
MENTAL DISABILITIES

ISSUE

Persons with a history of mental illness should not be excluded from Section 1411 of the Labor Code.

DISCUSSION

Assembly Bill 1126, Chapter 1189, spells out the safeguards in opportunity of persons to "....to seek, to obtain, and hold employment". This legislation forbids employers from discriminating against hiring solely on the basis of a physical handicap. This protection is not given to those with a history of mental illness. This appears to be a serious omission since a diagnosis of mental illness can range from mild personality disorder to chronic severe schizophrenia. Clients are understandably reluctant to give their true medical history due to the fear of being rejected when applying for employment. Persons with a history of mental illness often feel forced to lie in order to obtain a job for self-support. It is especially difficult for persons with a history of mental illness to be rejected for employment when they can demonstrate their ability to perform the job satisfactorily. Many would rather remain in a dependent welfare existence rather than face further loss of self-esteem by failing employment interviews.

RECOMMENDATION

45. THE DEPARTMENT OF HEALTH AND THE DEPARTMENT OF REHABILITATION ALONG WITH OTHER INTERESTED AGENCIES, SHOULD ATTEMPT TO INTRODUCE LEGISLATION TO HAVE ASSEMBLY BILL 1126 AMENDED. EMPLOYERS MAY NOT DISCRIMINATE AGAINST PERSONS SOLELY ON THE BASIS OF MENTAL ILLNESS. THOSE PERSONS WITH A HISTORY OF MENTAL ILLNESS WHO ARE MEDICALLY CERTIFIED TO BE ABLE TO PHYSICALLY AND MENTALLY PERFORM A GIVEN WORK ACTIVITY SHALL NOT AUTOMATICALLY BE EXCLUDED FROM EMPLOYMENT CONSIDERATION.

SUMMARY
MENTAL DISABILITIES

It is interesting to note and a compliment to the study committee and the conference participants that simplistic answers such as more money and more staff were seldom the primary recommendation as solutions to problems. In fact, the entire package of recommendations that came out of the conference are such that they could be implemented even in the most lean of economic times. Because of this, it appears that there is much reason to hope that the identified issues and resultant recommendations of the mental disabilities section are such in nature that they can see immediate response or progress.

AN ANNOTATED LIST OF POSITION PAPERS
AND OTHER RESOURCE MATERIAL

1. *Callaway, Lowell Southgate Convalescent Hospital
Difficulties in Working With Mentally Disabled.

2.**Collins, George, Mental Health Services, Los Angeles County A failure to Provide.

3. Collins, George, Los Angeles County Special Program Bureau
McGuire, Nanci, Los Angeles County, Program Development Bureau
Survey of Department of Rehabilitation and Los Angeles County Cooperative Programs.

4.**Denby, Wilhelmenia, Alameda County Mental Health Services
Mental Health Rehabilitation Services in Alameda County.

5. Detambel, Marvin, Department of Rehabilitation
Survey of Rehabilitation Services.

6. *Dörhen, Herbert, Ph.D., California State Psychological Association
Use of Licensed Psychologists

7. *Fitch, Nancy, Lompoc Mental Health Association
Need for Rehabilitation Centers.

8. *Goldbrandsen, Gene, Fontana Rehabilitation Workshop
Service Gap.

9. *Miller, Dorothy, California Society for Autistic Children
Improvement of Rehabilitation Services

10.**Newman, Leonard, Ph.D., Contra Costa County Medical Services,
Instant Placement.

11.**Sears, Margaret, National Association for Music Therapy
Music Therapy in Rehabilitation

12. *Switzer, Gail, Peninsula Children's Center
Need for Workshops and Supervised Living Arrangements.

* Letters regarding service needs
** Position papers.

NEURO-MUSCULO-SKELETAL DISABILITIES
OVERVIEW

PRECONFERENCE STUDY

The Neuro-Musculo-Skeletal Study Group held ten preconference public forums during the three months preceding the statewide Conference. Held in different areas throughout the state, these forums sought to give the different communities an opportunity to participate in the Conference by means of discussion of the needs of the disabled in the community and recommendations for solutions to be considered at the statewide Conference. These forums were attended by consumers, former consumers, providers of service, public and private agencies, and medical and rehabilitation professional staff.

CONFERENCE OVERVIEW
FROM ACCUSATION TO COOPERATION

The major issue discussed throughout all of the preconference forums was the role of the Department of Rehabilitation: What it does, what it does not do, and what it ought to do. There were many complaints of inadequate service and unmet needs. As the discussions progressed and by the time the statewide Conference convened, an awareness evolved that the Department of Rehabilitation was NOT and could not be the sole agency responsible for meeting all of the needs of the handicapped. At the statewide Conference, a spirit of cooperation had developed and discussions turned to the role of various agencies in meeting the needs of the disabled. The group began to realize that it takes many agencies working together, including consumer organizations supporting each other, to bring about the total rehabilitation of the severely disabled.

During the statewide Conference the Neuro-Musculo-Skeletal Study Group held three sessions at which there were 18 presentations based on matters discussed at the preconference forums. Disabled persons who were consumers or had been consumers of rehabilitation services made 17 of the presentations. These presentations demonstrated eight major issues of unmet needs and produced various recommendations for solutions. It was clearly pointed out that housing, transportation, recreation and employment were closely related. With inadequacies in one area, the efforts in other areas would be less successful.

The Neuro-Musculo-Skeletal Study Group was appropriately summarized by Gregory Sills, a consumer, who said, "Much has been done but there is much to do. The disabled felt free to express themselves and for the first time were confident that the professionals were listening."

MEDICAL CARE
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

Adequate medical care and the cost of it was one of the major concerns of the Neuro-Musculo-Skeletal Study Group. It is estimated that there are 1,100 incidents of spinal cord injury each year in the State of California, and that the cost of medical care for each in a lifetime can be $440,000.

DISCUSSION

Many communities and facilities do not have complete services for the spinal cord injury. These severely disabled persons need comprehensive service, including treatment, evaluation, development of adaptive devices, psychological adjustment, information on available resources and services which attend other unique problems. These kinds of services need to be provided before a severely disabled person can consider vocational rehabilitation. In many cases the individual receives these services in bits and pieces while he is expected to consider vocational rehabilitation. Such services can best be provided in a single facility located in various areas throughout the state, i.e., Rancho Los Amigos Project at L.A. County Hospital.

RECOMMENDATION

46. THE DEPARTMENTS OF HEALTH AND REHABILITATION SHOULD COOPERATE TO ESTABLISH REGIONAL CENTERS FOR THE NMS SEVERELY DISABLED PROVIDING COMPREHENSIVE SERVICES INCLUDING: TREATMENT, EVALUATION, PSYCHOLOGICAL ADJUSTMENT AND COUNSELING. SUCH CENTERS SHOULD BE FUNDED BY FEDERAL AND STATE FUNDS OR GRANTS.

ISSUE

The severely disabled usually have need for continuing medical care, which is prohibitive in cost. One reason why many of the severely disabled are employed in low income jobs is the fact that they are faced with the dilemma of either keeping their income low so that they can continue to receive Medicare or Medi-Cal, or take the risk of earning at levels that disqualify them for public health care services, and often result in less net income after paying their own medical expenses than they would receive on SSI.

RECOMMENDATION

47. CONSUMER ORGANIZATIONS AND ALL AGENCIES CONCERNED WITH THE SEVERELY DISABLED SHOULD WORK TOGETHER FOR THE INTRODUCTION AND PASSAGE OF FEDERAL AND STATE LEGISLATION WHICH WOULD ENABLE THE SEVERELY DISABLED TO CONTINUE TO RECEIVE MEDICARE AND/OR MEDI-CAL AFTER EMPLOYMENT, REGARDLESS OF EARNINGS.

INADEQUACY OF SSI
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

Although Supplementary Security Income is intended to provide the maintenance of the disabled and to be an incentive to return to employment, the NMS Study Group felt strongly that SSI is debilitating and a deterrent to employment.

DISCUSSION

The amount of income from SSI is insufficient to provide the severely disabled with adequate housing, transportation and special needs to live a full and worthwhile life. Consequently, the severely disabled are forced to manipulate their living arrangements in order to live within the SSI income and this destroys their sense of worth and dignity. If a severely disabled person goes to work, any income is immediately deducted from his SSI check and Medicare and Medi-Cal are terminated. Frequently the severely disabled have to take low-salaried jobs to enter the labor market. In addition, many of them must bear greater expense in order to get to and from work. Furthermore, if they require attendant or home-care service, they maybe disqualified for these services from the state because they are working and earning an income. Consequently, employment may not really improve their financial status. There is an obvious lack of information about attendant care, other social services and SSI in general. This has resulted in a great deal of confusion and dissatisfaction with the program. A number of recommendations evolved throughout the NMS preconference forums and the meetings of the Study Group at the Statewide Conference.

RECOMMENDATIONS

48. THE SOCIAL SECURITY ADMINISTRATION SHOULD HOLD SEVERAL MEETINGS THROUGHOUT THE STATE WITH THE SEVERELY DISABLED TO DISSEMINATE INFORMATION ABOUT THE SSI PROGRAM, AND TO LISTEN TO THE DISABLED AND THE PROBLEMS THEY ARE EXPERIENCING WITH THE SSI PROGRAM. THE DEPARTMENT OF REHABILITATION AND CONSUMER ORGANIZATIONS SHOULD STIMULATE SSA TO HOLD THESE MEETINGS AND, IF NECESSARY, SPONSOR THE MEETINGS AND REQUEST SSA REPRESENTATIVES TO ATTEND.

49. LEGISLATION SHOULD BE INTRODUCED TO PROVIDE FOR A REALISTIC SLIDING SCALE FOR DEDUCTING EARNED INCOME FROM SSI. SUCH LEGISLATION SHOULD BE PROMOTED BY CONSUMER GROUPS, THE DEPARTMENT OF REHABILITATION AND OTHER AGENCIES. THE ACT SHOULD BE AMENDED TO ENABLE SEVERELY DISABLED PERSONS TO CONTINUE TO RECEIVE FUNDS FOR ATTENDANT CARE AFTER THEY BECOME EMPLOYED UNTIL THEY CAN PROVIDE FOR THEIR OWN ATTENDANT, TRANSPORTATION, MEDICAL AND OTHER COSTS AND STILL HAVE SUFFICIENT INCOME TO LIVE ABOVE THE LEVEL OF SSI.

HOUSING AND ATTENDANT CARE
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

The severely disabled need adequate housing within their income and qualified attendants in order to participate in vocational rehabilitation and employment.

DISCUSSION

Some of the severely disabled need modified housing with ramps, wide doorways and other adaptations in order to function independently. Others need room and board facilities or group housing, with attendants. In most cases the housing needs to be near public transportation.

There is no agency responsible for a housing program for the severely disabled. In some areas the county social service worker will assist the client in locating housing; but adequate housing is usually not within his income. However, no agency has the funds to provide for supplementary housing cost on a continuing basis. The individual severely disabled person is left to his own resources.

Closely related to the problem of housing is the need for services from an attendant or homemaker services. There is no formalized training program for attendants of the severely disabled. Jobs for attendants are usually filled by persons who are willing to work for minimum wages; they usually have little or no knowledge of the needs of the handicapped. In a few instances this problem has been solved by group housing and the development of a pool of attendants. Such services are needed in more areas, particularly near college campuses.

RECOMMENDATIONS

50. THE SOCIAL SECURITY ADMINISTRATION SHOULD INCREASE HOUSING ALLOWANCES FOR THE SEVERELY DISABLED RECEIVING SUPPLEMENTAL SECURITY INCOME.

This recommendation can only be brought about through state and federal legislation. Individuals and consumer organizations must bring this need to the attention of their legislators. The Department of Rehabilitation should work with consumer groups, pointing out the need for adequate housing and attendants, and how the lack of such services affects rehabilitation of the severely disabled.

51. HALFWAY HOUSES AND GROUP HOUSING WITH ATTENDANTS FOR THE SEVERELY DISABLED SHOULD BE ESTABLISHED WITH SUBSIDIES FROM STATE AND FEDERAL FUNDS.

This could be implemented by local communities through revenue sharing funds or other grants. The Department of Rehabilitation should stimulate and advocate the program, but on the state level the Department of Housing and Community Development and on the federal level the Department of Housing and Community Development and on the federal level the Department of Housing and Urban Development should direct appropriate portions of their resources to the housing needs of the severely disabled.

52. STATE AND COUNTY SOCIAL SERVICE AGENCIES SHOULD DEVELOP A PROGRAM THAT PROVIDES ADEQUATE HOUSING FOR THE SEVERELY DISABLED.

53. THE DEPARTMENT OF EDUCATION IN CONSULTATION WITH THE DEPARTMENT OF REHABILITATION SHOULD IMPLEMENT A TRAINING PROGRAM FOR ATTENDANTS OF THE SEVERELY DISABLED IN COMMUNITY COLLEGES THROUGHOUT THE STATE.

TRANSPORTATION AND MOBILITY BARRIERS
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

Adequate transportation and a barrier-free environment are essential for the severely disabled to participate in training, employment and recreation.

DISCUSSION

Public transportation is a problem for the general public in most communities. The severely disabled as a group are more dependent on public transportation than the general group because their disability prevents them from driving without expensive adaptations, and they are usually dependent on a low income from SSI. Some communities have begun to be concerned about the lack of public transportation and its unavailability to the handicapped. Legislation has recently been enacted to increase funds for public transportation on the one hand and to remove mobility barriers for the handicapped on the other, but legislation is only the beginning. For example, the Bay Area Rapid Transit system is 90% barrier-free for paraplegics. It is impossible for people with mobility problems to get to and from BART without using a private car or buses which are not accessible to them.

As communities improve public transportation, they can make such transportation accessible to the disabled with little additional cost. Moreover, if they do not, the removal of barriers to the disabled will be much delayed, since the average lifetime of a new bus is 17 years and the cost of designing accessibility for the disabled into operating buses is prohibitive. Some communities have ramped curbs for wheelchairs but they will not be fully used until the severely disabled are able to use the public transportation. There has been recent federal and state legislation to remove mobility barriers and to make public transportation accessible to the handicapped, but it does not include all of the handicapped and changes have been slow in implementation. A few communities have begun to institute Dial-a-Ride service for senior citizens and the handicapped, but it is not available during the rush hours when the handicapped would be going to training facilities or jobs.

RECOMMENDATION

54. THE DEPARTMENT OF REHABILITATION SHOULD TAKE A STRONG ADVOCACY ROLE TO PROMOTE LEGISLATION AND ENFORCEMENT OF SUCH LEGISLATION TO CONSIDER THE NEEDS OF THE HANDICAPPED IN PUBLIC TRANSPORTATION SYSTEMS AND IN THE CONSTRUCTION OF BUILDINGS AND FACILITIES.

The Department of Rehabilitation has begun to assume this role and has established a Mobility Barriers Section. The Department has also funded programs for the removal of mobility barriers on campuses throughout the state. In addition, the Department's district offices have developed plans for working on the removal of barriers in their communities.

55. CONSUMER ORGANIZATIONS, LOCAL COMMUNITY BODIES AND LOCAL GOVERNMENT SHOULD INCLUDE THE HANDICAPPED IN PUBLIC TRANSPORTATION PROPOSALS AND WORK TOGETHER TO REMOVE ARCHITECTURAL BARRIERS.

LACK OF INFORMATION
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

There are a variety of services available for the severely disabled through public and private agencies and from consumer organizations. In some communities, services are more comprehensive than in others. However, in most areas there is a great lack of meaningful information about available services.

DISCUSSION

The severely disabled person himself must seek out services by going from one agency to another until he finds the appropriate source. Many times one agency is not acquainted with the services available from another agency, and the handicapped person becomes discouraged with the runaround of referral from one agency to another. The severely disabled person sometimes needs to move to a new community to live with or be near relatives, to have access to medical care, transportation, training and employment. A newly disabled person does not know where to begin to look for services. There is a need for a central source of information for the handicapped with accurate information on: Who provides what for whom and under what circumstances. Such a center providing information on transportation, medical care, housing, social service, welfare and rehabilitation would allow the disabled to more fully utilize available services, give them more independence and freedom of movement, and in general improve their lives and permit their more active participation in the community. Some organizations have developed directories of social services in an attempt to solve this problem. These directories are usually no more than a telephone directory. They are restricted to a given community and they quickly become outdated.

An information center for the handicapped with a toll free number, staffed with disabled persons who have had experience with the services of the various agencies, would be more meaningful to the handicapped.

RECOMMENDATIONS

56. A CENTER FOR INFORMATION TO THE HANDICAPPED SHOULD BE ESTABLISHED WITH A TOLL FREE NUMBER AND STAFFED WITH QUALIFIED HANDICAPPED PERSONS TO DISSEMINATE INFORMATION ON AVAILABLE SERVICES THROUGHOUT THE STATE. IT SHOULD BE FUNDED THROUGH FEDERAL AND OTHER FUNDS.

The Department of Rehabilitation and consumer organizations should advocate such centers and take an active role in bringing them about.

57. LOCAL COMMUNITIES SHOULD ESTABLISH PERMANENT COMMITTEES ON SERVICES TO THE HANDICAPPED COMPOSED OF HANDICAPPED PERSONS, AND AGENCIES SERVING THE HANDICAPPED, WITH THE PURPOSE OF SHARING INFORMATION ABOUT SERVICES AND REVIEWING THE NEEDS OF THE HANDICAPPED IN THE COMMUNITY.

Agencies serving the handicapped are not informed about the services and criteria for acceptance for services of other agencies serving the handicapped. There is a need for these agencies to become acquainted with the services of other

agencies and to educate the public.

58. LOCAL COMMITTEES NEED TO HAVE ONE ORGANIZATION, AGENCY, OR GOVERNMENTAL OFFICE TO BE RESPONSIBLE FOR THE CONTINUATION OF THEIR WORK AND FURTHER MEETINGS.

Some of the preconference forums for the state Conference established themselves as continuing committees and plan to meet periodically throughout the year. Some district offices of the Department of Rehabilitation have established local advisory committees with the same purpose. Other local committees for the handicapped have been established for some time and have varying degrees of success.

QUALITY OF DR SERVICE
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

The severely disabled need quality and comprehensive services to reach the goal of employment.

DISCUSSION

Many of the severely disabled clients or former clients of the Department of Rehabilitation who attended the preconference forums and the statewide Conference, expressed dissatisfaction with the fact that the Department of Rehabilitation is solely concerned with "vocational" services. They stated that the rehabilitation counselors are not sensitive to the needs of the severely disabled other than their employment needs. Some clients have experienced long delays between application and acceptance for service. Others have been given the impression that the counselor's goals are more important than the client's goals. Counselors working with the severely disabled should have a lighter caseload and should not be expected to rehabilitate the same number of clients as counselors who are not working with the severely disabled. Because of their special needs and the severity of their disability, severely disabled clients require more time and money to reach employment. The Department of Rehabilitation has been unable to meet the needs of the severely disabled because of its limited services and funds. There is a need for more counselors working with the severely disabled, more use of adaptive devices, and more research into occupations which can be performed by the severely disabled and into methods of working with the severely disabled.

RECOMMENDATIONS

59. THE DEPARTMENT OF REHABILITATION SHOULD PROVIDE SPECIALIZED TRAINING FOR REHABILITATION COUNSELORS WORKING WITH THE SEVERELY DISABLED TO DEVELOP THEIR SENSITIVITY TO THE NEEDS OF THE DISABLED AND TO ENABLE THE COUNSELORS TO COMMUNICATE EFFECTIVELY. THERE SHOULD BE AT LEAST ONE SPECIALIST COUNSELOR IN ALL DISTRICT OFFICES WORKING WITH THE SEVERELY DISABLED.

The Department of Rehabilitation began implementing some portions of the above recommendation prior to the statewide conference through special research and demonstration projects for the severely disabled. One project is at Rancho Los Amigos Hospital in Los Angeles, which is developing a training program for counselors working with the severely disabled. Another project concerns itself with adaptive devices. The Department is implementing this fiscal year a number of other projects which will explore ways to more effectively serve the severely disabled.

60. THE DEPARTMENT OF REHABILITATION SHOULD ESTABLISH A SPECIAL POSITION AS COORDINATOR OF SERVICES FOR THE SEVERELY DISABLED IN EACH REGIONAL OFFICE. THE COORDINATOR SHOULD BE RESPONSIBLE FOR COORDINATING SERVICES WITHIN THE REGION, SERVING AS A RESOURCE TO OTHER AGENCIES AND FUNCTIONING AS AN OMBUDSMAN FOR SEVERELY DISABLED CLIENTS.

Although this is a unique recommendation for services to the severely disabled, it has been implemented in part through the Client Assistance Project in Los Angeles. Similar projects have been implemented throughout the country. The purpose of such projects is to assist clients experiencing difficulty with services from the Department of Rehabilitation. The results of these projects will be carefully studied with a view of implementing the service on a larger scale and making departmental policy responsive to the needs of the disabled.

SEXUALITY AND THE DISABLED
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE:

Human sexuality is a basic need of the disabled as it is of the able-bodied and it is a critical part of total rehabilitation.

DISCUSSION:

The Neuro-Musculo-Skeletal Study Group felt that human sexuality for the disabled is grossly overlooked and ignored by the rehabilitation professional. Because of his inadequate adjustment, it frequently is the area which may be preventing the disabled person from fully participating in a vocational rehabilitation program. A panel discussion was presented which pointed out the need of the severely disabled for human sexuality.

The panelists believed that the vocational counselors do not have the knowledge, skills or the time to work with the disabled in the area of human sexuality; and usually usually avoid the subject. Frequently, they are unaware of the problem of sexuality for the severely disabled, either through insensitivity or lack of training. There are few, if any, places where a severely disabled person can find counseling or any other help in the area of sexuality. If the disabled person is lucky, he may be able to discuss the problem with another disabled person or solve his problem himself inadequately and with a feeling of more loss.

RECOMMENDATIONS

61. VOCATIONAL REHABILITATION COUNSELORS SHOULD RECEIVE TRAINING IN HUMAN SEXUALITY AND THE DISABLED. THE COUNSELORS SHOULD ATTEND THE COURSE OF HUMAN SEXUALITY AND THE DISABLED PROVIDED BY UC MEDICAL SCHOOL AT SAN FRANCISCO, WHICH SHOULD BECOME A PART OF THE GRADUATE PROGRAM IN REHABILITATION. COUNSELORS SHOULD BE ENCOURAGED TO WORK WITH THEIR CLIENTS IN THE AREA OF HUMAN SEXUALITY OR TO FIND OTHER PLACES WHERE THE DISABLED COULD RECEIVE COUNSELING.

MORE JOB OPPORTUNITIES
NEURO-MUSCULO-SKELETAL DISABILITIES

ISSUE

There is a lack of a variety of job opportunities for the severely disabled. They are usually employed in lower level jobs, such as sheltered shops or at the other end of the spectrum in professional occupations requiring a college education.

DISCUSSION

In skills and aptitudes, the majority of the severely disabled lie somewhere in the mid-range just like the rest of the population. Yet the service options open to them often seem limited to either sheltered or professional employment. The Federal Rehabilitation Act of 1973 mandates that state rehabilitation programs increase services to the severely disabled and the Department of Rehabilitation needs to be concerned about the employment of the severely disabled on all levels. The severely disabled also need training in job-seeking skills so they can contact employers themselves when they have marketable skills. Recent legislation (AB 1126) includes the handicapped under Fair Employment Practices, but the FEPC received no additional funds to effectively enforce the legislation.

RECOMMENDATIONS

62. THE DEPARTMENT OF REHABILITATION SHOULD PROVIDE MORE FUNDS TO WORKSHOPS TO ENABLE THEM TO PURCHASE MODERN EQUIPMENT, WHICH WOULD IMPROVE THE PRODUCTION CAPACITY OF THE SEVERELY DISABLED, PROVIDE MORE REALISTIC TRAINING FOR COMPETITIVE EMPLOYMENT.

63. THE DEPARTMENT OF REHABILITATION SHOULD DEVELOP A SPECIAL PROGRAM FOR PLACEMENT OF THE SEVERELY DISABLED.

64. THE DEPARTMENT OF REHABILITATION SHOULD PROVIDE TRAINING IN JOB-SEEKING SKILLS TO THE SEVERELY DISABLED AND TO ITS OWN STAFF SERVING THE SEVERELY DISABLED.

65. THE FEPC SHOULD RECEIVE ADDITIONAL FUNDS TO CARRY OUT THE ADDITIONAL ASSIGNMENT OF ENFORCEMENT OF FAIR EMPLOYMENT PRACTICES FOR THE PHYSICALLY DISABLED.

66. THE EMPLOYMENT DEVELOPMENT DEPARTMENT SHOULD ESTABLISH A SPECIAL PROGRAM FOR PLACEMENT OF THE SEVERELY DISABLED.

WRAP-UP SPEECH BY GREGORY SILLS
NEURO-MUSCULO-SKELETAL DISABILITIES

Fear Stifles - Change is Coming

Inherent Responsibilities

Lifestyle Alternatives

Strategies of Involvement

Anger Precipitates Action

These are a few of the feelings and phrases that have been expressed to us at this Conference, and to each of us they may have different meanings.

As I looked around our meeting in the last day and a half, I have seen beautiful things happening.

Most important, the disabled themselves are evident:

1. We are being allowed to express our feelings and ideas and know that the nondisabled in this room are listening.

2. But also, just as importantly -- we, the disabled, are no longer paranoid or simply angry in our comments and actions. We are developing some sophisticated ideas, strategies and programs.

We, the disabled, are seizing this opportunity to determine our future.

In this past day and a half, we have talked about and learned to:

Educate
Recreate
Communicate
Cooperate
Participate
Infiltrate
Litigate
Legislate and
Procreate

I question how sincere the Department of Rehabilitation is when it claims to service the severely disabled, and to be an advocate for all handicapped people. I would like to know what the Department, and I really mean each and every rehabilitation counselor, is doing in the areas of housing, transportation, legislation, architectural barriers, and so on. But you know the Department is way ahead of anyone else.

I sometimes wonder just what a large, potentially powerful organization like the Easter Seal Society does. Where are they in this movement?

The biggest culprits of all are the industrial insurers. Did you know that the number of clients they see each year, and the caseload monies they have, would

dwarf the entire State Department of Rehabilitation?

What the hell have these insurers ever done for the disabled? Compared to them, the Department of Rehabilitation is a radical movement.

What must be done is now obvious, for I think we all recognize within ourselves that inherent responsibility to be involved and to participate.

When we go back to our separate communities today, we must take these feelings and ideas with us. We will be letting ourselves down, as well as hundreds of thousands of others, if we do not begin or extend our efforts to alleviate the problems of all handicapped people.

Find out if in your area there is a Center for Independent Living, a Self-Help Incorporated, a chapter of C.A.P.H., or any other action group -- and volunteer and get involved. If none exist, start one. My own organization, C.A.P.H., started less than four years ago with five insightful people. Today we have 20 chapters in cities throughout California. Things can happen and work will get done.

What DR can do?

GENERAL

1. Assist groups developed for and by the consumer (financially, morally).

2. Push for regular spinal cord injury centers.

TRANSPORTATION

Be current, push for transbus and FAA regulations.

EDUCATION

Workshops - allow consumer inputs.

HOUSING

Think of housing as necessary to work, and be concerned with it.

ARCHITECTURAL BARRIERS

1. Litigate to enforce current legislation.

2. Have localized consultants throughout the state.

RECREATION

Encourage competitive sports as well as leisure activities, leading to life-style alternatives.

WELFARE

Seek to improve Supplemental Security Income requirements.

EMPLOYMENT

1. Make counselors more sensitive towards the disabled.

2. Identify "Equal Opportunity" employers.

3. Develop clients job-seeking skills.

If we didn't know it before, we know now that housing, transportation, employment and architectural barriers are not separate, one-dimensional problems. Each of these areas has many facets and is very much interrelated.

Housing is limited without transportation. Employment is impossible without transportation -- and it is aided by adequate housing.

Problems such as these and many more will be solved only when cooperation exists between the government, helping professionals and the disabled themselves.

We have seen and felt that cooperation at this Conference. We look forward to our future.

SHARED BEAUTY

I cannot see a rainbow's glory spread
across a rain-washed sky when storm is over;
nor can I see or hear the birds that cry
their songs among the clouds, or through bright clover.
You tell me that the night is full of stars,
and how the winds and waters sing and flow;
and in my heart I wish that I could share
with you this beauty that I cannot know.
I only know that when I touch a flower,
or feel the sun and wind upon my face,
or hold your hand in mine, there is a brightness
within my soul that words can never trace.
I call it Life, and laugh with its delight,
though life itself be out of sound and sight.

Robert J. Smithdas, Litt.D.

SENSORY DISABILITIES
OVERVIEW

The sensory disabilities presentation at the California Conference of Rehabilitation clearly demonstrated that the deaf and blind can plan and work together!

The exciting and well organized presentation made at the Conference did not happen by accident; rather, it was the culmination of much preconference planning and hard work among consumers, providers and educators. The sensory disabilities presentation clearly illustrated what can happen when people work together toward a common goal -- improving services for the blind, the deaf, and the deaf-blind.

The sensory disabilities presentation was composed of five main parts: What's New in Sensory Aids; Higher Education and the Handicapped -- Whose Responsibility?; The Deaf, the Blind and the Law; The Needs of the Multiply Handicapped; and, Independent Living Skills. Here is a brief overview of some of the main points presented in each of these five areas.

WHAT'S NEW IN SENSORY AIDS

A very important step in the development of sensory aids is ensuring that the public is made aware of the new developments. To this end, a very comprehensive review of new advances in sensory aids for the deaf and blind was presented.

It was pointed out that although rapid growth has taken place in the development of sensory aids, the impact of these new developments is just now being felt. Much additional work and research is necessary before many of these new sensory aids are ready for public use.

It was emphasized that many new aids for the blind will complement rather than provide a substitute for the walking cane and guide dog. In other words, canes and guide dogs will continue to serve very important functions for some time to come.

Perhaps the most important point made and one which had unanimous approval was that sensory aids should be available for those who need them -- and those who need them should plan an important role in deciding what sensory aids should be developed.

HIGHER EDUCATION AND THE HANDICAPPED -- WHOSE RESPONSIBILITY?

A position paper by Frank Laski was presented on the handicapped individual's right to an equal opportunity for an education.

A panel reacted to the paper and some of the following points were made. We need to look at this issue from the viewpoint of "what's best for the handicapped student", rather than who's responsible for providing what services. In determining what's best for the handicapped student, we need to involve the handicapped student. In fact, the student has a responsibility for vocalizing his or her needs to make sure he or she is involved.

It was agreed by everyone that we must be aware of the needs of the handicapped if we are to be of assistance to them. This involves working with the handicapped rather than for the handicapped. We need to avoid making the handicapped dependent on others -- they are capable and should have the responsibility for directing their futures.

Lastly, everyone agreed that no one person or group is responsible for the education of the handicapped -- it's a group project and we all need to work together.

THE DEAF, THE BLIND, AND THE LAW

The everyday problems encountered by the sensory disabled due to misunderstanding and ignorance on the part of the public was vividly demonstrated through live skits in this presentation.

Have you ever considered what it might be like trying to get a room for the night in an unfamiliar town if you are totally blind? How about trying to explain why you need Supplemental Security Income if you are totally deaf and the person you are trying to "communicate" with is indifferent to your circumstance?

A picture is worth a thousand words and the skits literally "spoke" for themselves. Attorneys watching the skits made the important observation that the handicapped cannot simply accept what agencies tell them at face value; consumer groups often need agency regulations so they know what benefits and services they are entitled to.

THE NEEDS OF THE MULTIPLY HANDICAPPED

It was pointed out in this presentation that most deaf-blind individuals do not have a language. Since they lack a language, they are unable to express and make their needs known. This inability of the deaf-blind to make their needs known has resulted in their needs being overlooked and unattended to.

Fortunately, the needs of the deaf-blind came across "loud and clear" during this presentation. Their number one need is for companionship -- they are lonely. What they would most like is someone to talk to. A very compelling point was made that the time you spend with a deaf-blind individual will not only help him or her -- it will also be a rewarding experience for you!

Again, it was emphasized that if the deaf-blind are to be served effectively, a coordinated effort will be needed among all the service agencies.

INDEPENDENT LIVING SKILLS

The knowledge and resources are available in this society to properly serve the handicapped; however, how well have we really done? The answer to this question is we have never really accepted those who look, sound, or move differently than us. Since we haven't accepted the handicapped, we haven't provided the services of which we are capable and to which the handicapped are entitled.

This problem is particularly pressing when we think of the multiply handicapped -- those individuals who not only have sensory disabilities but additional problems such as cerebral palsy, mental retardation, amputations -- the list is endless. The very legitimate point was made that these individuals have special problems, therefore, they need special help from special people with special skills -- presently California lacks this type of service.

SUMMARY

There is no substitute for attending and becoming involved in a Conference with such a fine mission as the one held in Sacramento on rehabilitation. One really had to be there to feel and appreciate what took place.

For those who could not attend, these brief notes may have given at least a flavor of what took place. For those who did attend, perhaps these notes will stir up good feelings for things that happened at the Conference -- especially at the Sensory Disabilities Section meeting.

SENSORY AIDS
SENSORY DISABILITIES

ISSUE

Many sensory handicapped people are unnecessarily dependent on others, and are subject to health or safety hazards because they are unable to acquire various sensory aids which would make them independent.

RECOMMENDATIONS

67. A TEST IN THE COURTS OF THE STATE SHOULD BE UNDERTAKEN WHICH MIGHT ESTABLISH THE INHERENT RIGHT OF A PERSON TO OBTAIN NECESSARY ADAPTIVE AIDS TO FUNCTION INDEPENDENTLY IN THE COMMUNITY.

68. ORGANIZATIONS OF AND FOR THE SENSORY HANDICAPPED SHOULD ADVOCATE FOR HEALTH CARE LEGISLATION WHICH WOULD PROVIDE SENSORY AIDS TO THOSE DEAF OR BLIND WHEN IT COULD BE DETERMINED THE SENSORY AIDS WOULD ENABLE THE DEAF OR BLIND PERSONS TO: INCREASE THEIR LEVEL OF INDEPENDENCE; ENHANCE THEIR EDUCATIONAL OPPORTUNITIES; ENABLE THEM TO OBTAIN SUITABLE EMPLOYMENT; OR ENABLE THEM TO ESTABLISH NORMAL RELATIONS WITH A NON-HANDICAPPED POPULATION.

ISSUE

Deaf and blind people are frequently enrolled in college programs which are not suited to their needs because there is no overall planning for educational service for them.

DISCUSSION

Educational services at the college level are provided to deaf and blind persons through a network of national college programs, specialized programs for deaf and blind persons in regular college and community college programs, and through instruction in integrated classes. However, the development of these diverse educational services has taken place without an overall plan or meaningful planning between the institutions providing the services.

RECOMMENDATIONS

69. AN INDEPTH STUDY BY A TASK FORCE COMPOSED OF REPRESENTATIVES OF CONSUMER ORGANIZATIONS, EDUCATORS, AND REHABILITATION SPECIALISTS SHOULD BE UNDERTAKEN TO DETERMINE THE ADVANTAGES AND DISADVANTAGES OF EACH TYPE OF EDUCATIONAL SERVICE IN REGARD TO THE VARIOUS TYPES OF DEAF AND BLIND PEOPLE WHO CAN BENEFIT FROM STUDY AT THE COLLEGE LEVEL. SUCH A TASK FORCE SHOULD ADOPT A PLAN FOR THE ORDERLY DEVELOPMENT AND COORDINATION OF A POSTSECONDARY EDUCATIONAL SYSTEM FOR ALL DEAF AND BLIND PEOPLE IN CALIFORNIA AND SHOULD DEVELOP GUIDELINES FOR STAFFING AND CURRICULUM THAT WOULD ENSURE MAINTENANCE OF A MINIMUM LEVEL OF QUALITY.

ISSUE

Deaf and blind individuals have a difficult time obtaining a college level education because of the different standards for providing services between the Department of Rehabilitation and various colleges.

DISCUSSION

Both the Department of Rehabilitation and the various institutions of higher education in the state share responsibility for the provision of educational support services, vocational and educational counseling and job placement. This sometimes results in the buck being passed between the rehabilitation agency and the educational institution to the detriment of the sensory handicapped person who wants to go to college. It also means that if a person is deaf or blind, he or she must pass a double set of educational admission standards: the requirements prescribed by the college and also the criteria established by the Department of Rehabilitation.

RECOMMENDATIONS

70. A DETERMINATION OF A DEAF OR BLIND PERSON'S LEGAL RIGHT TO HIGHER EDUCATION AND TO THE NECESSARY SUPPORT SERVICES SHOULD BE MADE BY A TEST CASE IN COURT SIMILAR TO THE CASE RECENTLY FILED ON BEHALF OF MENTALLY RETARDED PEOPLE.

71. THE DEPARTMENT OF REHABILITATION SHOULD DEVELOP A CLEAR STATEMENT OF THE RIGHTS HANDICAPPED PEOPLE HAVE TO SERVICES PROVIDED BY THE DEPARTMENT AND SHOULD INSTITUTE A PUBLIC INFORMATION PROGRAM TO INFORM HANDICAPPED PEOPLE OF THESE RIGHTS.

ISSUE

Many educators and rehabilitation specialists believe that deaf and blind students are inadequately prepared for college level study by the secondary education programs in the state.

RECOMMENDATIONS

72. AN INDEPTH STUDY SHOULD BE CONDUCTED TO DETERMINE IF DEAF AND BLIND STUDENTS WHO GRADUATE FROM CALIFORNIA HIGH SCHOOLS HAVE ACHIEVED THEIR MAXIMUM POTENTIAL IN REGARD TO PREPARATION FOR A COLLEGE LEVEL PROGRAM OF STUDY. BASED ON THE FINDINGS OF THIS STUDY, MODIFICATIONS IN CURRICULUM AND TEACHING METHODS IN SECONDARY SCHOOLS SHOULD BE MADE. THE STUDY SHOULD ALSO MAKE RECOMMENDATIONS FOR THE ESTABLISHMENT OF APPROPRIATE COLLEGE PREPARATORY REMEDIAL EDUCATION PROGRAMS THAT CAN HELP CURRENT GRADUATES MAKE THE TRANSITION FROM TODAY'S HIGH SCHOOLS TO COLLEGE LEVEL PROGRAMS.

LEGAL ASPECTS
SENSORY DISABILITIES

ISSUE

Large numbers of persons who are deaf or who are blind face needless discrimination in regard to employment, education, and access to public buildings.

RECOMMENDATION

73. A CONCERTED JOINT EFFORT BY ORGANIZATIONS OF AND FOR THE SENSORY HANDICAPPED AND BY REHABILITATION AND EDUCATIONAL ORGANIZATIONS SHOULD BE LAUNCHED TO INFORM DEAF AND BLIND PEOPLE OF THEIR RIGHTS WHICH HAVE BEEN ESTABLISHED THROUGH RECENT STATE AND FEDERAL LEGISLATION AND THROUGH COURT DECISIONS IN CALIFORNIA AND OTHER STATES.

DEAF-BLIND
SENSORY DISABILITIES

ISSUE

Deaf-blind individuals are frequently denied services that are intended specifically for deaf people or for blind people.

RECOMMENDATION

74. SPECIAL TRAINING SHOULD BE PROVIDED TO PROFESSIONALS WHO SPECIALIZE IN SERVING DEAF PEOPLE OR BLIND PEOPLE SO THAT THEY COULD EXTEND THEIR SERVICES TO THOSE INDIVIDUALS WHO ARE BOTH DEAF AND BLIND. TRAINING IN SPECIAL COMMUNICATION METHODS USED BY DEAF-BLIND, FOR EXAMPLE, WOULD ENABLE COUNSELOR-TEACHERS FOR THE BLIND TO ALSO MEET THE NEEDS OF THE DEAF-BLIND.

ISSUE

Because of the severity of their handicap, many persons who are both deaf and blind are not known to professional workers in the field.

RECOMMENDATION

75. AS A FIRST STEP IN PLANNING TO MEET THE SERVICE NEEDS OF PERSONS WHO ARE BOTH DEAF AND BLIND, A MAJOR STATEWIDE EFFORT SHOULD BE MADE, AT PUBLIC EXPENSE, TO COORDINATE THE IDENTIFICATION OF ALL CITIZENS OF THE STATE WHO ARE BOTH DEAF AND BLIND. SUCH A STUDY WOULD INCLUDE OUTREACH PROGRAMS WITH NURSING HOMES, RESIDENTIAL TREATMENT FACILITIES, THE MEDICAL COMMUNITY AND SIMILAR RESOURCES.

ISSUE

A full complement of services should be available wherever there is a sufficient number of deaf-blind individuals.

RECOMMENDATION

76. AN INVENTORY OF SERVICES WHICH MIGHT BE ADAPTED TO MEET THE NEEDS OF DEAF-BLIND PEOPLE SHOULD BE MADE IN EACH MAJOR COMMUNITY OF THE STATE.

77. LOCAL CHAPTERS OF ORGANIZATIONS OF DEAF PEOPLE AND OF BLIND PEOPLE SHOULD BE ENCOURAGED TO INCLUDE DEAF-BLIND IN THEIR SOCIAL AND RECREATIONAL PROGRAMS.

ISSUE

Deaf-Blind people frequently are unable to take advantage of services which are provided at public expense to other individuals.

RECOMMENDATION

78. ALL PUBLICLY SUPPORTED AGENCIES WHICH PROVIDE SERVICE TO THE GENERAL PUBLIC SHOULD BE REQUIRED TO MAKE SUITABLE INTERPRETER SERVICES TO AVAILABLE TO DEAF OR DEAF-BLIND APPLICANTS FOR SERVICE.

INDEPENDENT LIVING SKILLS
SENSORY DISABILITIES

ISSUE

There are many blind individuals residing in California who are in need of counselor-teacher services.

DISCUSSION

Large areas of California are not served by skilled counselor-teachers for the blind. Persons who suffer the loss of vision and reside in these unserved areas have little professional help available to them in their efforts to overcome the problems of blindness. This results in their unnecessary dependence on other people for support in their activities of daily living. This is emphasized by the 1949 Joint Legislative Interim Report on services to the blind that stated there should be one counselor-teacher per 1,000 blind people. However, the current ratio is 26 counselor-teachers per 40,000 blind population.

RECOMMENDATION

79. THE DEPARTMENT OF REHABILITATION SHOULD BE MANDATED BY LAW TO PROVIDE THE SERVICES OF SKILLED COUNSELOR-TEACHERS FOR THE BLIND IN ALL AREAS OF CALIFORNIA.

ISSUE

There is an extreme shortage of facilities which are needed to help deaf children and adults, including those that facilitate transition from their home setting and/or from state operated residential schools to independent community living.

RECOMMENDATION

80. PUBLIC SUPPORT SHOULD BE PROVIDED FOR THE DEVELOPMENT OF MENTAL HEALTH AND ADJUSTMENT FACILITIES AND TRANSITIONAL LIVING FACILITIES FOR DEAF CHILDREN AND/OR ADULTS IN MAJOR COMMUNITIES THROUGHOUT THE STATE.

ISSUE

There is a lack of coordination of adjustment to blindness and adjustment to deafness programs which are residential in nature with those which are provided on a day treatment basis or are provided by itinerant counselor-teachers.

RECOMMENDATIONS

81. A SPECIAL STUDY TASK FORCE WHICH INCLUDES CONSUMERS, SERVICE PROVIDERS, AND EDUCATORS SHOULD BE APPOINTED TO DEVELOP A COMPREHENSIVE STATEWIDE PLAN FOR THE DEVELOPMENT OF ADJUSTMENT TO SENSORY DISABILITY SERVICES. SUCH A PLAN COULD BE USED TO GUIDE THE ORDERLY DEVELOPMENT AND COORDINATION OF SERVICES PROVIDED BY PUBLIC AND PRIVATE AGENCIES.

ANNOTATED LIST OF PAPERS
PRESENTED TO THE SENSORY DISABILITIES STUDY GROUP

1. Foulke, E. Alternatives to the visual display of information. Paper presented to the Sensory Disabilities Study Group Report.
   Paper reviews the systems now being developed to aid individuals with visual impairments through improved braille and recording techniques. Devices such as the Triformation as well as systems such as the ARTS (Audio Response Time Sharing) are described.

2. Laski, F. Postsecondary education and handicapped students, some legal considerations. Paper presented at the California Conference on Rehabilitation, Sacramento, October 1974.
   The purpose of this paper is to "shed some light" on the complex issue regarding handicapped students' rights to postsecondary education. The paper is not presented as a legal brief; however, a review of relevant legal decisions is presented. Court actions on education for handicapped, state constitutions and statutes, federal laws, as well as the topic of "equal protection of the law" are covered in the paper.

3. Hingson, F. The disservice of service. Paper presented at the California Conference on Rehabilitation, Sacramento, October, 1974.
   This paper is by a blind student whose message is that blind students should be provided only those services that will enable them to compete with other students. The writer explains in his paper why the blind student should be provided only those services will give them an opportunity for an equal education.

4. MacFarland, D.C. The rehabilitation services administration's role in the rehabilitation of deaf-blind persons. 1980 is now: A conference on the Future of Deaf-Blind Children. Los Angeles, John Tracy Clinic, 1974.
   Paper reviews the events which led up to the development of the proposal for the Center for Deaf-Blind Youths. The three major programs of the center are reviewed and the implications the center has for future planning are presented.

5. Reese, R. Full time interpreter position for the deaf. Paper presented at the California Conference on Rehabilitation, Sacramento, October, 1974.
   In this paper the California program manager for services to hearing impaired individuals presents his rationale for establishing full-time interpreter positions in the Department of Rehabilitation.

6. Ross, S.L. Beyond education for the handicapped: overcoming barriers of access to employment, transportation and buildings. Paper presented at the California Conference on Rehabilitation. Sacramento, October, 1974.
   This paper summarizes the recent legal efforts in California to make employment, public transportation, and buildings as accessible to handicapped individuals as they are to non-handicapped individuals.

7. Saunders, F.A. Recent developments in sensory aids for the deaf. Paper presented at the California Conference on Rehabilitation, Sacramento, October, 1974.
This paper provides a very comprehensive review of the latest developments in sensory aids for individuals with severe hearing impairments.

8. Scadden, L.A. Recent advances in sensory technology for the blind. Paper presented at the California Conference on Rehabilitation, Sacramento, October, 1974.
This paper provides a very comprehensive review of those recent technological advances that may be of value to individuals with visual impairments.

9. Schlesinger, H. and Reese, R. Independent living skills for deaf persons, Paper presented at the California Conference on Rehabilitation, Sacramento, California, October, 1974.
Paper recommends three special service programs for prevocationally deafened individuals. The programs recommended are mental health facilities, adjustment facilities and transitional living facilities.

10. Urena, M. Cost benefit considerations regarding sensory aids. Paper presented to the Sensory Disabilities Committee for inclusion in the Sensory Disabilities Group Report.
This paper discusses some of the issues involved in purchasing expensive sensory aids for clients of the Department of Rehabilitation. The author suggests several principles which should be observed in deciding who is eligible for sensory aids. Several issues regarding the purchase of sensory aids for individuals needing them to increase their independence rather than required for employment are also discussed.

DEVELOPMENTAL DISABILITIES
OVERVIEW

PRECONFERENCE PLANNING AND INFORMATION GATHERING

Preconference planning involved representatives and organizations for developmentally disabled persons from throughout the state. Inquiry groups were impaneled in nine strategic geographical areas of the state. The goal of these groups was to provide for consumer and advocate input. The meetings were publicized and took place in Redding, San Diego, and many points in between. Individuals from small communities participated equally with persons from major metropolitan areas. Many of the needs identified were common to urban and rural consumers alike. Others reflected geographical needs. All individual disability groups participated actively. The concern for increased and improved programs was universal. The inquiry process proved very valuable. It was fully worth the time and energy expended. The active participation of consumer advocates as panel members and presenters added a dimension of solidarity not often seen. The Program Manager for Developmental Disabilities had the opportunity to meet with and hear many citizens with concerns about the program. Some administrative changes have taken place reflecting these concerns.

Presentations and position papers from the inquiry groups were tabulated and eight major areas of concern evolved. The following were dealt with at the Conference:

1. General Supportive Services, Case Finding, Coordination and Guardianship.
2. Treatment (Medical, Dental, Physical Therapy, etc.).
3. Educational Services (Adult Education, Junior College).
4. Counseling and Family Support.
5. Living Arrangements.
6. Vocational Services (Evaluation, Sheltered Employment, Activity Centers).
7. Transportation
8. Funding of Services

CONFERENCE OVERVIEW

There were over 300 people interested in the problems of the developmentally disabled. Prior to breaking up into four discussion groups, the participants listened to presentations by Betty Dieckmann, Chief of Program Planning and Development, Department of Rehabilitation, in the morning and Aline Colgate, Director of Special Services, Elwyn Institute, in the afternoon.

Miss Dieckmann substituted for Miriam Stubbs of the R.S.A. She discussed "What's in the Rehabilitation Act of 1973." She stressed the increasing impact disabled people are making toward shaping laws and environment to meet needs that have been traditionally ignored.

Ms. Colgate talked of her organization and the proven results of intensive concern and work with developmentally disabled individuals.

Following each talk the four discussion groups met in separate locations. Although the large number of people made discussion somewhat unwieldly, it was gratifying to see such widespread involvement.

Each group began their discussions with expressions of frustration at having to face a myriad of agencies and regulations in their day-to-day work for the developmentally disabled. All four groups focused on the Department of Rehabilitation to facilitate services for the developmentally disabled. The Department of Rehabilitation was cast in the role as coordinator, advocate, enforcer of existing laws for the handicapped and initiator of new legislation in behalf of the handicapped, primarily because it sponsored the Conference. All groups were aware of the basic legislative limitations on the Department of Rehabilitation and were fundamentally asking for departmental assistance in carrying recommendations to agencies responsible for the specific areas of concern.

Recommendations or issues will be discussed in this report as they pertain to the broad areas mentioned above. However, the Conference groups made no recommendations for areas 2, 4, and 5.

The various agencies representing developmentally disabled people commend the Department of Rehabilitation for its farsightedness in creating the special statewide program for the developmentally disabled. The agencies also strongly encourage the strengthening of the developmentally disabled program and ask that the recommendations in this Conference report be acted upon by the Department of Rehabilitation.

GENERAL SUPPORTIVE SERVICES,
CASE FINDING, COORDINATION AND GUARDIANSHIP
DEVELOPMENTAL DISABILITIES

ISSUE

There is an acute lack of statewide knowledge of the problems of the developmentally disabled.

DISCUSSION

There is little coordination of efforts throughout the state to focus upon the needs of the developmentally disabled. This Conference demonstrates its value because it brings interested people together to discuss needs, techniques of service and most importantly serves as a vehicle for communication.

RECOMMENDATION

82. THE DEPARTMENT OF REHABILITATION IS URGED TO PROVIDE NOT ONLY BIENNIAL CONFERENCES BUT ALSO LOCAL CONFERENCES TO MOBILIZE LOCAL COMMUNITY COMMUNICATION AND ACTION.

ISSUE

The disabled are still relegated to the fringes of society and many potential clients are unaware of Department of Rehabilitation services.

DISCUSSION

The disabled need to be seen as a part of society rather than a segment apart without function and mostly without identity. The Department of Rehabilitation's outreach has not been extensive enough to identify potential clients.

RECOMMENDATION

83. THE DEPARTMENT OF REHABILITATION IS URGED TO DO MORE PUBLIC INFORMATION AND AWARENESS WORK. THE DEPARTMENT SHOULD BE MORE AGGRESSIVE IN CASE FINDING WITH THE SEVERELY DISABLED.

ISSUE

The greatest triumph a disabled person can have is to be able to be independent of others.

DISCUSSION

Eligibility criteria for rehabilitation services are too restrictive and often prohibit serving the disabled on the basis of his need to become as independent as possible.

RECOMMENDATION

84. THE DEPARTMENT OF REHABILITATION IS URGED TO ADVOCATE AND SUPPORT FEDERAL LEGISLATION TO MANDATE INDEPENDENT LIVING SERVICES AS EXPRESSED IN THE COMPREHENSIVE SERVICES PORTION OF THE VETOED (NIXON) REHABILITATION ACT. NEW ELIGIBILITY CRITERIA SHOULD BE ESTABLISHED THAT ARE BASED ON NEEDS AND NOT LABELS.

ISSUE

Barriers, architectural and attitudinal, limit disabled people to dependent statuses.

DISCUSSION

Severely disabled people are effectively denied their constitutional right to life, liberty and the pursuit of happiness by needless obstructions to functioning.

RECOMMENDATION

85. THE DEPARTMENT OF REHABILITATION IS URGED TO ACTIVELY PURSUE ARCHITECTURAL BARRIER LAW ENFORCEMENT.

86. FEPC LEGISLATION MUST BE PUSHED BY THE DEPARTMENT OF REHABILITATION TO INCLUDE THE MENTALLY DISABLED. (ATTITUDINAL BARRIERS WITHIN THE DEPARTMENT MUST BE ATTACKED.)

ISSUE

Many people are denied employment because of their disability.

DISCUSSION

Rehabilitation Act of 1973, Section 504, says any recipient of federal funds must have an affirmative action plan for disabled people. This includes public employers. Irrelevant job tests have long excluded disabled people from employment.

RECOMMENDATION

87. THE DEPARTMENT OF REHABILITATION IS URGED TO PURSUE AN ACTIVE AND AGGRESSIVE AFFIRMATIVE ACTION PLAN WITH ALL EMPLOYERS ESPECIALLY THOSE RECEIVING FEDERAL FUNDS. THE DEPARTMENT OF REHABILITATION IS ALSO ASKED TO PURSUE ELIMINATION OF IRRELEVANT JOB TESTS.

ISSUE

Federal regulations tend to work against SSI and SSDI recipients who wish to try to become self-supporting despite the so-called trial work period.

DISCUSSION

Severely disabled people understandably lack confidence in their ability to become self-supporting. Present regulations threaten to stop income payment if the disabled demonstrate they can do some kind of work. The trial work period does not consider a deteriorating physical condition following the work period.

RECOMMENDATION

88. THE DEPARTMENT OF REHABILITATION IS URGED TO ADVOCATE LEGISLATION THAT WOULD CHANGE SSI AND SSDI REGULATIONS (ESPECIALLY SSI) WHICH INHIBIT CLIENTS FROM ATTEMPTS AT SELF-SUPPORT OR SCHOOLING BEYOND AGE 18.

EDUCATIONAL SERVICES (ADULT AND JUNIOR COLLEGES)
DEVELOPMENTAL DISABILITIES

ISSUE

Developmentally disabled individuals are not being allowed the opportunities to use adult education and junior colleges.

DISCUSSION

The opportunities to use community educational institutions are lacking because programs are few and too restrictive to allow developmentally disabled people to utilize them.

RECOMMENDATION

89. THE DEPARTMENT OF REHABILITATION IS URGED TO HELP IN THE DEVELOPMENT AND COOPERATE IN THE EXPANSION OF SERVICES TO THE DEVELOPMENTALLY DISABLED IN ADULT EDUCATION AND COMMUNITY COLLEGES.

ISSUE

There is a lack of prevocational services in schools at all grade levels for developmentally disabled individuals.

DISCUSSION

The provision of the prevocational services could lead to more vocational opportunities for developmentally disabled individuals. School cooperative programs seem to adequately demonstrate the fact.

RECOMMENDATIONS

90. THE DEPARTMENT OF REHABILITATION SHOULD PROVIDE PREVOCATIONAL AND COMMUNITY LIVING SKILLS AS WELL AS VOCATIONAL SERVICES AT ALL SCHOOL LEVELS. (E.G. EXPANDED COOPERATIVE PROGRAMS).

ISSUE

Developmentally disabled pupils and particularly autistic children do not have the opportunity to benefit from appropriate public education.

DISCUSSION

The lack of influence of the schools is due to limited educational focus on the problems of developmentally disabled and the autistic child.

RECOMMENDATION

91. THE DEPARTMENT OF REHABILITATION IS URGED TO ADVOCATE WITH THE DEPARTMENT OF EDUCATION TO PLACE MORE EMPHASIS ON DEVELOPMENTALLY DISABLED PUPILS WITH BEHAVIOR INTERVENTION IN THE CASE OF AUTISTIC CHILDREN.

ISSUE

"Normal" children are often isolated from the disabled. The isolation leads to an early categorization of a disabled person that is lifelong.

DISCUSSION

The fact of segregation abnormally influences children to reject or continue the isolation of "different" people as a lifelong pattern.

RECOMMENDATION

92. THE DEPARTMENT OF REHABILITATION IS URGED TO ADVOCATE WITH THE DEPARTMENT OF EDUCATION TO INTEGRATE NORMAL AND SPECIAL EDUCATION CLASSES TO THE EXTENT FEASIBLE IN ORDER TO NORMALIZE EACH CHILD'S CONCEPT OF DISABILITY SO THAT ACCEPTANCE OF DISABLED PEOPLE WILL OCCUR AT AN EARLY AGE.

VOCATIONAL SERVICES
(EVALUATION, SHELTERED EMPLOYMENT, ACTIVITY CENTERS)
DEVELOPMENTAL DISABILITIES

ISSUE

Prevocational help is often necessary long before a person becomes employable.

DISCUSSION

The present Department of Rehabilitation policy is too circumscribed particularly with developmentally disabled people, who generally take longer to learn and to properly evaluate.

RECOMMENDATION

93. THE DEPARTMENT OF REHABILITATION IS REQUESTED TO REASSESS THE TIME A PERSON CAN ENTER THE REHABILITATION SYSTEM. THE DEPARTMENT OF REHABILITATION IS ASKED TO BECOME A PURCHASER OF SELF-HELP AND PREVOCATIONAL SERVICES PRIOR TO NEED FOR VOCATIONAL SERVICES.

ISSUE

Department of Rehabilitation counselors' caseloads are too large.

DISCUSSION

More counselor time and attention is required to work with the developmentally disabled people.

RECOMMENDATION

94. THE DEPARTMENT OF REHABILITATION SHOULD REDUCE CASELOAD SIZE FOR EACH COUNSELOR.

ISSUE

Counselors should be encouraged to work with more severely disabled people.

DISCUSSION

The pressure for numbers causes counselors to work with easier cases. Closures of hard cases should be recognized.

RECOMMENDATION

95. THE DEPARTMENT OF REHABILITATION IS URGED TO CHANGE THE ACCOUNTABILITY SYSTEM TO ENCOURAGE COUNSELORS TO WORK WITH SEVERELY DISABLED PEOPLE.

ISSUE

It takes special skills to work with developmentally disabled people.

DISCUSSION

One of the reasons developmentally disabled people are avoided by counselors is that they lack information and expertise to be effective.

RECOMMENDATION

96. COUNSELORS WORKING WITH THE DEVELOPMENTALLY DISABLED MUST BE PROVIDED WITH ADVANCED TRAINING BY DEPARTMENT OF REHABILITATION

TRANSPORTATION
DEVELOPMENTAL DISABILITIES

ISSUE

Severely disabled people are not accorded equality in the use of public transportation.

DISCUSSION

The severely disabled are prisoners of their environment by reason of architectural barriers and a paucity of finances. Transportation barriers removed often spell the difference in the fullness of life a severely disabled person can pursue.

RECOMMENDATION

97. THE DEPARTMENT OF REHABILITATION SHOULD ADVOCATE WITH THE DEPARTMENT OF TRANSPORTATION TO EXPAND TRANSPORTATION NETWORKS TO INCLUDE RURAL AREAS SPECIFICALLY AND TO ACCOMMODATE THE SEVERELY DISABLED ON PUBLIC TRANSPORTATION. SPECIAL FARES FOR DISABLED PEOPLE SHOULD ALSO BE PURSUED.

FUNDING OF SERVICES
DEVELOPMENTAL DISABILITIES

ISSUE

Funding for regional centers is insufficient for all services to the developmentally disabled.

DISCUSSION

Persons who are developmentally disabled but not retarded are not being served by all regional centers. Transportation systems for regional center patients are needed and not available because of inadequate funding.

RECOMMENDATIONS

98. THE DEPARTMENT OF REHABILITATION IS URGED TO ADVOCATE WITH THE DEPARTMENT OF HEALTH TO PRESS TO EXPAND REGIONAL CENTER FUNDING TO ALLOW FOR SERVICES AT ALL LEVELS NEEDED, INCLUDING ALL SUBSTANTIALLY HANDICAPPED DEVELOPMENTALLY DISABLED PERSONS.

ISSUE

Grant information is often overlooked as a source of additional funding.

DISCUSSION

There is always a shortage of adequate funding for any rehabilitation program. No opportunity should be overlooked as a source of expanding services.

RECOMMENDATION

99. THE DEPARTMENT OF REHABILITATION IS URGED TO ESTABLISH A CLEARING HOUSE FOR GRANT INFORMATION AND A NOTIFICATION SYSTEM TO ALL INTERESTED PARTIES.

ISSUE

Unrealistic rate structures to workshops keep programs mediocre.

DISCUSSION

Adequate fees and longer evaluation will permit workshop upgrading. It is believed that a serious study should be made of current salary and piecework concepts in workshops.

RECOMMENDATION

100. THE DEPARTMENT OF REHABILITATION SHOULD CHANGE RATE STRUCTURES OF REHABILITATION FACILITIES. RATES MUST BE MORE RESPONSIVE TO COST.

ISSUE

State funds are not enough to attract more matching federal funds.

DISCUSSION

Everyone in all groups was acutely aware of the fact that Department of Rehabilitation turns back many federal dollars each year simply because the state will not put up more desperately needed funds.

RECOMMENDATION

101. THE DEPARTMENT OF REHABILITATION SHOULD BE RESPONSIBLE FOR ADVOCATING THAT STATE FUNDS BE MADE AVAILABLE SO THAT ALL FEDERAL FUNDS EARMARKED FOR CALIFORNIA BE UTILIZED.

THE LAST RECOMMENDATION MADE BY THE DEVELOPMENTALLY DISABLED CONFERENCE GROUP WAS A STRONG REQUEST FOR SPECIFIC RESPONSES TO ALL OTHER RECOMMENDATIONS WITHIN SIX MONTHS OF THE CONFERENCE'S END BY THE DEPARTMENT OF REHABILITATION.

ANNOTATED LIST OF POSITION PAPERS
AND RESOURCE MATERIALS
DEVELOPMENTAL DISABILITIES

1. Advance Foundation, Inc.
   Department of Rehabilitation Matching Funds Policy

2.**Amaral, Madelyn
   Early Therapy and Diagnosis and Gaps in Services

3.**Anderson, Audrey
   Early Help with Neurologically Handicapped

4.**Arenburg, Stanley I.
   L.A. Police Department
   Needs to Understand Problems of Autistic People.

5. Association for the Mentally Retarded, Inc., Contra Costa County
   Present Laws Need Changing to Really Help Retarded.

6.**Azusa Unified School District
   The Forgotten Severely Disabled Children

7. Bachlor, C.R., McDonnell Douglas
   Astronautics Company
   Prediction of Epileptic Seizures

8.**Barnsdale, Mrs. Amelia A.
   The Unique Problems of the Blind Retarded

9. Baro, Walter, MD
   Value of Epileptic Centers

10. W. T. Butner
    The Cerebral Palsied Adult: After 21 -- What?

11. California Association for Neurologically Handicapped Children, Contra Costa.
    Statement to Developmental Disabilities Inquiry Group on Needs of Developmental Disabled People.

12. California Association for Neurologically Handicapped Children
    Needed Service System for Neurologically Handicapped Children.

13. California Association for Neurologically Handicapped Children.
    Special Teacher Training for Educating the Minimum Brain Damaged Child.

14. California Association for Neurologically Handicapped Children.
    Vocational Planning for those with Minimal Brain Damage.

15. California Association for Retarded Resolution No. 7 and No. 11
    More Training Facilities for Retarded. Priority Dental Care for Retarded.

16. California Epilepsy Society
Epilepsy Information Sheet

17. Cohen, Muriel
Housing Needs for Institutionalized Retarded

18. Comprehensive Health Planning Council, L.A. County
Comprehensive Service for Retarded

19. Conway, Mrs. Oliver
Programs and Facilities for Autistic Individuals

20. Developmental Disabilities Planning and Advisory Council, Alameda
Department of Rehabilitation Expands Services to Developmental Disabilities

21. Developmental Disabilities Council of Contra Costa County, Inc.
Proposed Program, Contra Costa DD Center

22. Developmental Disabilities, San Jose Inquiry Group
Developmental Disabilities Needs for Employment and Money for New Programs.

23. Developmental Disabilities Board Area 11
Rehabilitation Services

24. Developmental Disabilities Board Area 9
Vocational Needs

25. Developmental Disabilities Board Area 10
Leisure, Prevocational and Vocational Services

26. Developmental Disabilities Board Area 12
Rehabilitation Services

27. Developmental Disabilities Board Area 13
Rehabilitation Facility Model

28. EPI-HAB Rehabilitation
Epilepsy and Comprehensive Needs

29. Exceptional Children's Foundation
Implementation Vocational Rehabilitation Act, 1973.

30. Fairhaven Guild for the Retarded, San Diego, California
Equipment and Tools for Their School

31. Frank, Donald S.
Three Cities Job Clinic and Services System Manual

32. Gaboury, May, 1974
Operationalizing Consumer Involvement

33. Great Oaks Village, Inc. of San Diego, California
Development of Rudolf Steiner Village.

34. Jaross, Mrs. R.
Needs of Blind Retarded People.

35. Leech, Mary E.
Normalization of the Developmentally Disabled

36. Los Angeles County Chapter of California Society for Autistic Children, Inc. and National Society for Autistic Children, Inc.
Health Needs of the Autistic Child.

37. Los Angeles County Chapter of California Society for Autistic Children, Inc. and National Society for Autistic Children, Inc.
Comprehensive Rehabilitation Services for Autistic People.

38. Los Angeles Chapter, National Society for Autistic Children
Civil Rights of Autistic People.

39. Los Angeles County Epilepsy Society
Problems of Epileptic Children and Adults.

40.**Los Angeles City Unified School District
Rehabilitation Needs Coordination of Services for Developmentally Disabled People.

41. L.A. School System
Vocational Training Services for Mentally Retarded in Public Schools Survey (Nov. 1973.)

42. McMahon, Dan
Epilepsy and Insurance Problems.

43.**Marsella, Armando, CPA
Special Job Opportunities - Autistic People.

44. Michigan Epilepsy Center Association
Attitude Affecting the Epileptic

45. Miller, Viola, Orange County Epilepsy
Civil Service Excludes the Epileptic

46. Morgan Center
Special Training for Developmentally Disabled Children.

47.**National Society for Autistic Children, Sacramento Chapter
Basic Program for the Autistic Person

48. Nevada County Community Workshop
Realistic Modification of SSI Program

49. Nevada County Workshop Staff
A Formula for Consumer Involvement

50. Orange County Epileptic Society
Need of a Clinic for Epileptics in Orange County

51. Ostrin, Louis
Lack of Trained Personnel to Work with Autistic

52. Paster, Arelene
The Needs of Adolescent of Young Adult Autistic People.

53. Presentation to the Inquiry Panel on Rehabilitation needs of the Developmentally Disabled. San Francisco Comprehensive Health Planning Council. Requires Vastly Improved Services.

54. Pritchett, Elaine, Oakland Inquiry Group.
Need for Housing, Transportation and Recreation for the Epileptic

55. San Diego Chapter, National Society for Autistic Children
Specific Urgent Needs of Autistic Children

56. San Diego County Epilepsy Society
Independent Living Skills for Epileptics

57. San Francisco Comprehensive Health Planning Council
Developmental Disabilities County Plan

58. Sevick, Cherrie, San Diego Association for the Retarded
Rehabilitation of Severely Disabled Adults: Whose Responsibility?

59. Seymour, Lillian-Vocational Committee, California Association for Neurologically Handicapped Children.

60. Singer, Julia Ann
Preschool Psychiatric Center for Children with Learning Problems.

61. Sonoma County Citizen Advocacy Project
Filling the Gaps in Services to Developmentally Disabled Individuals.

62. Taylor, Michael S.
Epilepsy and the Department of Motor Vehicles: An Unclear Policy.

63. Training Development Service, Santa Ana and San Diego.

64. United Cerebral Palsy Center, San Diego, California
The Transportation-Architectural Barriers-Sheltered Care-Workshops.

65.**Weber, Jordon, Attorney At Law
Autism and Housing Uninstitutionalized.

66. Wiscot, Arthur L., M.D.
Unmet Needs of Autistic Children.

**Letters received by Study Group

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